# 2021 ESG REPORT

Going beyond - every day

ultragenyx



# FORWARD-LOOKING STATEMENTS & OTHER IMPORTANT LEGAL INFORMATION

This document and the materials or websites cross-referenced contain statements that are aspirational or reflective of our views about our future performance that constitute "forward-looking statements" within the meaning of the Private Securities Litigation Reform Act of 1995. Forward-looking statements are generally identified through the inclusion of words such as ("aim," "anticipate," "aspire," "believe," commit," "endeavor," "estimate," "expect," "goal," "intend," "may," "plan," "seek," "strive," "target," "will," and "work," or similar statements or variations of such terms and other similar expressions. The forward-looking statements in this document and the materials or websites cross-referenced concern the Company's goals, progress or expectations with respect to corporate responsibility, sustainability, patients, products, product candidates, employees, environmental matters, policy, and business risks and opportunities. Forward-looking statements inherently involve risks and uncertainties that could cause actual results to differ materially from those predicted in such statements. These statements are based on numerous assumptions that we believe are reasonable, but are open to a wide range of uncertainties and business risks. In addition, these statements may be based on standards for measuring progress that are still developing, controls and processes that continue to evolve, and assumptions that are subject to change in the future. Consequently, actual results may vary materially from what is contained in a forward-looking statement. For a further description of the risks and uncertainties that could cause actual results to differ from those expressed in these forward-looking statements, as well as risks relating to the business of Ultragenyx in general, see Ultragenyx's Annual Report on Form 10-K filed with the Securities and Exchange Commission (SEC) on February 15, 2022 and its subsequent periodic reports filed with the SEC. Forward-looking statements are aspirational and are not guarantees or promises that goals or targets will be met. The Company undertakes no obligation to update any forward-looking or other statements, whether as a result of new information, future events, or otherwise, and notwithstanding any historical practice of doing so. The Company may determine to adjust any goals and targets or establish new ones to reflect changes in our business. The information included in, and any issues identified as material for purposes of, this document may not be considered material for SEC reporting purposes. In the context of this report, the term "material" is distinct from, and should not be confused with, such term as defined for SEC reporting purposes. Website references and hyperlinks throughout this document are provided for convenience only, and the content on the referenced third-party websites is not incorporated by reference into this report, nor does it constitute a part of this report. The Company assumes no liability for the content contained on the referenced third-party references.

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# **ABOUT THIS REPORT**

Ultragenyx Pharmaceutical Inc. (Ultragenyx) is headquartered in Novato, California. We have offices and laboratories in 12 countries across North America, Europe and Latin America and are planning to expand to Asia in 2022. In the U.S., we have offices and/or laboratories in California, Florida, Massachusetts, Texas and Utah.

This report contains environmental, social and governance (ESG) disclosures for the period January 1 through December 31, 2021, unless otherwise noted. The scope of our 2021 ESG Report is Ultragenyx's wholly owned operations globally. Third-party manufacturing is not included.

The term "employees" refers to our full-time employees, while the term "workforce" is used to refer to the wider groups of people working for and with us, including full- and part-time employees and contingent staff.

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### CONTACT

We welcome your feedback. Please contact us at <u>esg@ultragenyx.com</u> with your comments and suggestions about this report.

# LETTER FROM OUR CEO

### Dear Stakeholders,

As a physician and researcher, I have worked with many families touched by rare diseases. I was fortunate to be present when the first patients were successfully treated with therapies for multiple conditions that previously had no treatment. Those moments have stayed with me, and they are the reason I founded Ultragenyx – to create more of those moments for individuals living with rare and ultra-rare diseases.

We are in the golden age of rare disease medicine. With new modalities becoming available in the last decade and with earlier diagnosis, we have the opportunity to avoid the complications that can come with disease progression. We can give children born with rare diseases a very different future, and we have the chance to dramatically change people's lives.

# We Are Going Beyond... For Patients

We go beyond the limits of traditional development and delivery of new medicines, endeavoring to make a higher quality of life possible for those living with rare and ultra-rare diseases. Our commitment to patients starts at the earliest stage of our scientific development process, and we are committed to collaborating with them every step of the way. Our approach honors the privilege of impacting lives

and reflects our shared urgency to accelerate the timelines for delivering safe and effective new medicines to patients in need. Our commitment doesn't end with developing a treatment. We price responsibly and make every effort to make our therapies accessible to anyone who needs them through robust patient navigation and physician support programs and through our expanded access programs. We also partner with patient advocacy groups to provide education and support to the rare disease community.

When starting Ultragenyx, we decided that we would be generous with our knowledge. For families putting together research and development efforts, it is hard to accrue the skills and experience needed to undertake development of a new therapy. We are committed to helping the rare disease community by sharing our science and expertise to advance future drug development, whether by us or others. This includes helping families put together research and development efforts and hosting a recurring RARE Entrepreneur Bootcamp, an event geared towards educating and mentoring families and foundations with research and development efforts underway.

# **For Our People**

We operate under a fundamental principle that our success as a company is inextricably tied to the success and health of our people. Our efforts to take care of our workforce go beyond compensation and professional development to include programs and tools that improve and prioritize physical and mental well-being. Our efforts foster a deeper sense of connection to our mission to bring novel therapies to individuals living with rare and ultra-rare diseases with the utmost urgency and care.

Our commitment extends to potential new hires. To achieve equity in healthcare, we must achieve equity in our workplace. We are focused on recruiting and interviewing in a merit-based manner, which means removing unconscious bias related to race, gender, age and other factors. For those that are new to our space, we seek to provide a seminal first exposure to the biotechnology industry by creating a sense of belonging from the very start.

# For Communities Where We Live & Work

One seed of kindness can make a real difference in our communities, and our employees plant those seeds by volunteering their time, serving on boards of nonprofit organizations and giving back where they can. We also provide corporate donations to organizations providing support to rare disease families and other at-risk communities. We believe that each individual action matters and that the sum of those individual actions has a noticeable impact.

### For the Environment

Our day-to-day decisions have an impact on the environment. That's why we're designing and building our new gene therapy manufacturing facility in Massachusetts with sustainability in mind. One area of focus has been energy efficiency. We expect to save more than half a million kilowatthours of electricity annually by going beyond what's required. We're also developing an environmental strategy to responsibly manage our future footprint.

# **Every Day.**

We built Ultragenyx from the ground up with a commitment to sustainability ingrained from the very start. That's evidenced by the accomplishments mentioned in the pages of this inaugural report. This report introduces our ESG strategy and is a meaningful evolution of our exciting ESG journey. We commit to reporting annually and to being transparent about our performance, progress and challenges. I am proud of what we have accomplished since our founding in 2010 and I look forward to Ultragenyx leading the sustainable future of rare disease medicine.





Emil D. Kakkis, M.D., Ph.D.

Founder, President and CEO

# **Awards & Recognitions**

 Emil Kakkis received the Life Science Leadership Pantheon award from California Life Sciences



• A top 25 company in the 2021 Deloitte Technology Fast 500™



Recognized as a
 Best Place to
 Work 2022
 by BioSpace



 Recognized as one of the fastest growing middle market companies by the San Francisco Business
 Times and Silicon Valley Business Journal

# **ABOUT US**

Ultragenyx Pharmaceutical Inc. (Ultragenyx) is a biopharmaceutical company headquartered in Novato, California, that is committed to bringing novel products to patients for the treatment of rare and ultra-rare diseases, with a focus on serious, debilitating genetic diseases. Our purpose is to lead the future of rare disease medicine as we seek to treat individuals afflicted by diseases with limited or no treatment options, and we recognize that their lives and well-being are dependent upon our efforts to develop new therapies. For this reason, we are passionate about developing these therapies with the utmost urgency and care.

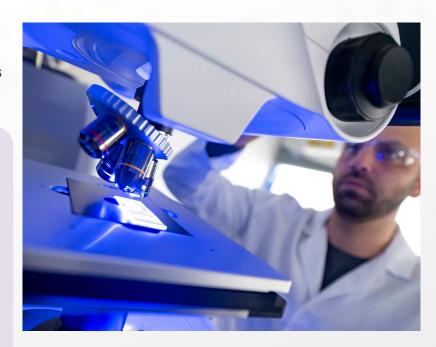
We follow a set of operating principles that we call our <u>Rare Formula</u> to guide development of our business, pipeline and people in support of our mission and goals. We believe that building a successful and sustainable rare disease-focused company requires both the right expertise and the will to do the right thing for the rare disease communities every day. Therefore, we are committed to engaging patients and their families from the earliest stages of therapeutic development and develop our programs with majority access in mind.

Our commercial footprint spans North America, the European Union, Switzerland, the United Kingdom, Latin America and other select international markets. Our commercial organization is highly specialized and focused, due to the nature of rare disease diagnosis and treatment. Our patient diagnosis liaisons educate physicians to help confirm diagnoses of patients; our UltraCare Liaisons educate physicians regarding our approved therapies; and our UltraCare Guides support patients and their families with treatment or financial needs.

# **Ultragenyx by the Numbers**

- Founded in **2010**
- 1,100+ employees
- 402,600 square feet of office and laboratory space in 12 countries
- 112,500 square-foot gene therapy manufacturing facility under construction in Massachusetts
- 126 clinical sites in 17 countries

We also have a compassionate use program for those seeking access to investigational therapies that are not yet approved by applicable regulatory authorities, as well as programs to provide free medicine to patients who are actively navigating the reimbursement process for an approved therapy.



# **Our Medicines**

Therapy Type	Product Name	Therapeutic Area	Disease(s)
Monoclonal Antibody	CRYSVITA® burosumab  Kyowa Kirin collaboration	Bone Endocrine	X-Linked Hypophosphatemia (XLH) Tumor-Induced Osteomalacia (TIO)
	(evinacumab-dgnb) Injection  Regeneron collaboration (Marketed outside the U.S. by Ultragenyx)	Metabolics	Homozygous Familial Hypercholesterolemia (HoFH)
Enzyme Replacement	Mepsevii (vestronidase alfa-vjbk)	Metabolics	Mucopolysaccaridosis VII (MPS VII)
Substrate Replacement	DOJOLVI° TRIHEPTANOIN	Metabolics	Long-Chain Fatty Acid Oxidation Disorders (LC-FAOD)

# **Highlights**

### TO DATE:

- 3 first FDA-approved rare disease treatments for 4 diseases.
  - o Crysvita®: X-linked hypophosphatemia (XLH) & tumor induced osteomalacia (TIO)
  - o Mepsevii®: Mucopolysaccharidosis VII (MPS VII)
  - o Dojolvi®: Long-chain fatty acid oxidation disorders (LC-FAOD)
- Over 380 patients in 43 countries
   have been approved for access to
   Ultragenyx treatments through various
   global expanded access and patient
   assistance programs since 2013.
- 6 clinical programs in diseases with no approved disease-modifying therapies.
- Over \$335,000 donated to local small catering businesses to provide lunches and snacks to pandemic first responders, and at-risk communities in the Boston and San Francisco areas during the pandemic (2020-2021).

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ESG GOVERNANCE & STRATEGY

Ultragenyx's ESG strategy is guided by a materiality analysis that helps us prioritize resources to address the topics that could have a significant impact on our business and that matter most to our stakeholders.





# **ESG GOVERNANCE**

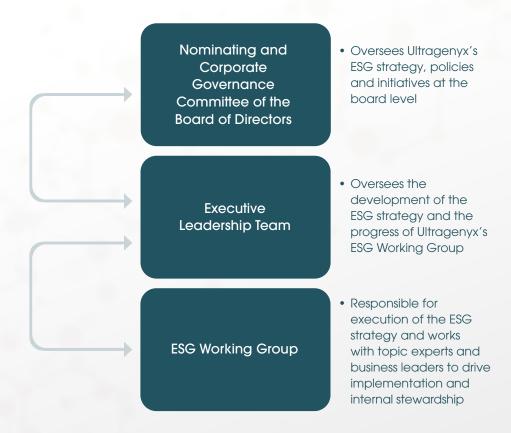
Since our founding, Ultragenyx has had a strong commitment to ethics, integrity and corporate responsibility. This commitment is centered around partnering with the rare disease community, improving access to treatments, maintaining a people-first culture and investing in innovation.

During the past year, we hired an ESG leader to build on this strong foundation and take the initial steps to become more deliberate in how we understand the risks and opportunities associated with ESG issues, how we manage them and how we communicate our impact to our stakeholders. This standalone ESG report will become an annual publication on our efforts and progress in ESG. It covers a growing and evolving set of business practices across our organization, from how we develop and manufacture our medicines prioritizing safety and accessibility, to nurturing a diverse, equitable and inclusive culture for our employees, to supporting our communities and protecting the environment.

On a regular basis, the Nominating and Corporate Governance Committee of our board of directors reviews and makes recommendations on the company's ESG strategy, policies and initiatives. The ESG Working Group, sponsored by the chief financial officer and the chief human resources officer, frequently reports to the executive leadership team on the company's ESG progress.

# **Looking Ahead**

Moving forward, we expect our ESG journey to include setting goals and targets to propel progress and increased transparency around relevant performance data.



# MATERIALITY ANALYSIS

In 2021, we conducted a materiality analysis. Both internal and external perspectives were considered in evaluating our ESG priorities. Prioritizing the ESG topics that could have a significant impact on our business and that matter to our stakeholders enables us to focus on the appropriate issues, communicate more effectively internally and externally, and ultimately allocate our resources to ESG efforts that create long-term value and have a positive impact on our shareholders and society.

We have taken an integrated and intentional approach to ESG and launched a new strategic framework to formalize and structure our initiatives.

# **Material ESG Topics**

Based on our materiality analysis, we developed our ESG framework with five pillars: Patients, People, Communities, Planet and Governance. These pillars inform the structure of this report and are guiding the development of our ESG strategy, starting with the identification of broad aspirations and objectives, highlighted at the beginning of each chapter.

Material topics are listed below each pillar; bolded topics have been identified as high priority:

# **Evaluate relevant ESG topics**

Evaluated best practice guidelines from ESG reporting standards (SASB, etc.) and conducted peer benchmarking to identify important ESG topics impacting our business

### **Assess the impact** on Ultragenyx

Conducted discussions and surveys with internal topic experts and business leaders to rank the ESG topics on their importance to our business and their ability to impact our stakeholders

### Topic prioritization taking into account importance to stakeholders

Obtained external stakeholder feedback from analyst reports, investor queries, data from Datamaran (an Al-driven tool) and other resources to determine prioritization of topics

### **Patients:**

- Access & Affordability
- Clinical Trial Practices
- Patient Safety & Product Quality
- Innovation
- Impact

### People:

- Employee Equity, Diversity & Inclusion
- Employee Health & Safety
- Workforce Management

### **Communities:**

• Community Relations

### Planet:

- Climate Change Risks & Management
- Energy Management
- Product Stewardship
- Waste Management
- Water Management

### Governance:

- Ethical Practices & Corporate Behavior
- Governance Structures & Mechanisms
- Human Rights
- Management of the Legal & Regulatory Environment
- Privacy & Data Protection
- Risk Management & Business Continuity
- Transparency

# Patients: Innovation & Impact

Going Beyond to Lead the Future of Rare Disease Medicine

### We are committed to going beyond for patients by:

- Developing life-changing treatments for rare and ultra-rare diseases.
- Partnering with the rare disease community by sharing our science and expertise to advance development of new treatments, whether by us or others.
- Achieving majority access to our medicines.
- Engaging and supporting the rare disease community with education and resources.





# **ASPIRATION:**

To share our science and expertise to lead the future of rare disease drug development and to treat as many individuals with rare diseases as possible



OBJECTIVES	OUR PROGRESS
Develop best-in-class disease- modifying treatments for rare diseases in a rapid, safe and efficient manner	<ul> <li>Three first FDA-approved rare disease treatments for four diseases since 2017 with six clinical programs currently in development.</li> <li>~ 5.5 year average development timeline, from entering the clinic to approval, compared to about 7-7.5 years for our peers.</li> </ul>
Foster industry-wide and community funded development efforts in rare and ultra-rare diseases	<ul> <li>Over 85 individuals representing over 65 organizations have attended our RARE Entrepreneur Bootcamp since 2017.</li> <li>Strategic licensing collaborations with biopharmaceutical companies, including recent agreement with Regeneron to develop, commercialize and distribute Evkeeza® (evinacumab) in countries outside the U.S.</li> <li>Over \$2.2 million donated to over 100 rare disease patient advocacy groups in 18 countries.</li> <li>Participation in five industry consortia to support collaborative drug development.</li> </ul>
Achieve majority access through responsible pricing and support services	<ul> <li>Over 380 patients in 43 countries have been approved for access to Ultragenyx treatments through various global expanded access and patient assistance programs since 2013.</li> <li>400 active participants enrolled in 55 investigator sponsored clinical trials.</li> </ul>
Use our expertise to amplify the voices of the rare disease community to inform and influence key decision makers in the field of rare disease	Founding member of the Rare Disease Company Coalition to engage and educate policymakers on priority issues in rare disease.

# INNOVATION

Innovation refers to our processes, initiatives, activities and investments aimed at the efficient and rapid advancement of product candidates that maximize patient health outcomes. Our patient-centric drug development model and our collaboration with others support our critical mission to advance life-changing treatments quickly and effectively to patients in need.

We believe innovation in healthcare is critical for the many individuals living with rare diseases who are waiting for an approved treatment. We make significant investments in research and development and have entered into strategic licensing collaborations with other bio-pharmaceutical companies to innovate and develop new therapies. Please see <u>Our Partners</u> for more information.

We seek patent protection in the United States and internationally for our products, product candidates and processes. Our policy is to patent or in-license the technologies, inventions and improvements that we consider important to the development of our business. This policy helps us mitigate risk as well as accelerate the drug development process for the benefit of patients. For more details, please see our 2021 Annual Report. As of December 31, 2021, we own, jointly own or have exclusive rights to:

- More than 160 issued and in-force patents.
- More than 325 pending patent applications, including more than 50 pending U.S. applications.

Our research aims to advance a new program into a clinical trial every one to two years. As of the end of 2021, we had four rare disease treatments approved by the U.S. Food and Drug Administration (FDA) and six novel programs that advanced into clinical trials.



# Our Patient-Centric Drug Development Model

**Objective:** Develop best-in-class disease-modifying treatments for rare diseases in a rapid, safe and efficient manner

Three of our four approved medicines are the only FDA-approved therapy for their respective diseases. More than 90% of rare diseases do not have available treatments, so we dedicate ourselves every day to the goal of providing treatments where none currently exist.

Our commitment is based on the fundamental principles of advancing innovative life-changing treatments as quickly as possible and effectively providing these treatments to patients in need.

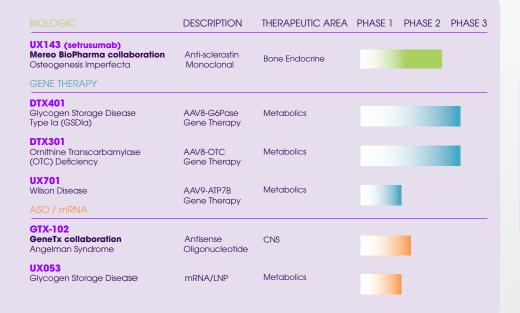
We employ a dynamic drug development model that is designed to engage with patients and caregivers at every stage, from research through delivery and commercialization. Our collaboration with patients is critical to drug development in rare disease, where these individuals and their caregivers are the experts on the treatment outcomes that matter. Our endpoint development and strategy team, comprised of a highly qualified medical and scientific research group,

conducts investigations into the basic mechanisms of disease during early and late-stage clinical development of medicines, while also engaging patients and their caregivers to understand how a disease affects their lives.

The insights provided by this level of collaboration help us design programs that evaluate a treatment based on both its clinical benefit and its ability to have a meaningful impact on an individual's daily life.

### **Clinical Pipeline**

Our current approved therapies and clinical-stage pipeline consist of four modalities: biologics, small molecules, gene therapies, and nucleic acid therapies (antisense oligonucleotide (ASO) and messenger RNA (mRNA)). We have a broad translational research effort that works to turn observations in the laboratory and clinic into interventions that improve the health of individuals with rare and ultra-rare diseases. We are advancing clinical and preclinical development programs across multiple rare disease therapeutic areas. Please see <a href="Our Pipeline">Our Pipeline</a> for further information.



# ~ **5.5** years

Average number of years from entering the clinic to approval compared to ~7 to 7.5 years for our peers

Crysvita® and Mepsevii® were both developed in fewer than five years.

## **Quality & Patient Safety**

Our company's reputation is dependent on the trust that patients, healthcare professionals and the general public place in us. We are committed to the highest levels of quality, safety and efficacy. These principles are reflected in the research, development and manufacturing of our products.

We comply with laws, regulations and international standards regarding quality and patient safety:

- We are committed to complying with applicable laws, regulations and international standards dealing with Good Laboratory Practices, Good Manufacturing Practices and Good Clinical Practices (collectively "GxP"), and our employees undergo annual GxP training.
- We require our suppliers and business partners to adhere to similar high standards when performing work for or on behalf of the company, and we require that they comply with the Drug Supply Chain Security Act (DSCSA).

# Zero FDA inspections or recalls issued

that materially and adversely impacted our business during fiscal year 2021. Please refer to our <u>2021</u> <u>Annual Report</u> for more information.

# Disease Monitoring Programs & Post-Marketing Commitments

Ultragenyx developed the novel concept of a disease monitoring program (DMP) to evaluate the long-term outcomes for newly approved therapies, facilitate knowledge sharing with the rare disease community, and go beyond fulfilling any post-marketing regulatory requirements. A DMP is a global, non-interventional trial that assembles regulatory-quality data on a broad population of individuals living with a rare disease, whether treated – via commercial access to a drug – or not. DMPs go beyond clinical trials by enhancing the understanding of the disease and its treatment for the benefit of patients, physicians, payers and the company.

We partner with patient advocacy groups to provide information to patients and support their participation in our DMPs. DMPs are conducted both in and out of the clinic to provide access to broader and more diverse patient populations, including those living in countries and regions where other types of clinical studies are not feasible.

We provide participants in our DMPs with the opportunity to receive their own data in easy-to-understand language and view comparisons with similar patients on or off therapy. For more information on data sharing in DMPs, see this peer-reviewed journal article, co-authored by our CEO, Emil Kakkis.

Ultragenyx **launched the first DMP in 2012.** To date, we have **initiated five DMPs,** including one for Crysvita® for the treatment of X-linked hypophosphatemia (XLH). This is our largest study, with over 700 patients in its third year. Our most recent DMP – for Dojolvi® – was initiated in 2021.

# How DMPs Provide Value to Multiple Stakeholders

- DMPs provide **rare disease patients** with the opportunity to receive their own data in plain language and view comparisons with similar patients. By providing progress reports with graphs and explanations, the DMP contributes to their understanding of their disease.
- DMPs provide **healthcare providers** the opportunity to assess quantitative outcomes in their patients as well as analyze data from a broader rare disease patient population.
- Researchers gain high quality information on the disease for development of other tools, product candidates or discoveries.
- Reimbursement authorities gain supportive data on long term outcomes and impacts with fewer data gaps and data quality issues.
- For Ultragenyx, DMPs provide longitudinal data that is used to complete our post-marketing commitments. The data also advances the science of each therapy and promotes further research, such as in dosing and efficacy.

# **Clinical Trials**

Our clinical trials are conducted worldwide and are designed to evaluate the safety and efficacy of our product candidates. We are committed to conducting trials in an ethical manner and we follow internal procedures and policies, the International Council for Harmonization of Technical Requirements for Pharmaceuticals for Human Use/Good Clinical Practice (ICH/GCP) principles, and national and local regulations for trial design and conduct. We also seek to protect patient safety and well-being through appropriate informed consent procedures and good clinical practices. Safety is regularly monitored throughout the course of clinical trials and discussed with participating investigators. We document and report relevant safety information and adverse events (AEs), such as any new or worsening conditions, to worldwide regulatory authorities.

# 9 new protocols

Registered by Ultragenyx in 2021 on www.clinicaltrials.gov

# Clinical Trial Recruitment & Site Selection

Our clinical programs often represent studies of firstever treatments for diseases that, by definition, have a low prevalence. We take pride in going beyond for individuals with rare disease by making our clinical trials inclusive and diverse - available in multiple countries to patients regardless of gender, ethnicity or socioeconomic status. We have a dedicated Patient Find team that works with clinical operations and development teams to find participants, and our clinical and disease monitoring program trials include sites in developing and low-income countries whenever possible. We also fulfill compassionate use requests or requests for investigator sponsored trials (or both) for our clinical and approved products, which often come from low-income countries where we do not have clinical sites.



**investigator sponsored trials (ISTs)** approved with >400 clinical participants enrolled



## **Clinical Trial Data Transparency**

Data transparency is essential to fostering trust with patients, healthcare professionals, regulatory agencies and medical researchers. We recognize this importance and support the overall principles of greater clinical trial data transparency as part of our patient-centric drug development model.

We follow the standards and principles set forth by organizations such as:

- The International Federation of Pharmaceutical Manufacturers & Associations (IFPMA).
- European Federation of Pharmaceutical Industries and Associations (EFPIA).
- Japan Pharmaceutical Manufacturers Association (JPMA).
- Pharmaceutical Research and Manufacturers of America (PhRMA).

Additionally, Ultragenyx is a member of the Biotechnology Innovation Organization (BIO) and follows the BIO Position Statement on Clinical Trial Registries and Dissemination of Clinical Trial Results.

We endeavor to make clinical trial information and results public in a timely manner while protecting essential proprietary information and patient privacy.

Ultragenyx registers protocol information for company sponsored clinical trials of investigational and marketed products in accordance with applicable laws and regulations. In the U.S., protocol information is registered at <a href="https://www.clinicaltrials.gov">www.clinicaltrials.gov</a>.

Ultragenyx discloses the results of company sponsored clinical trials in accordance with applicable laws and regulations. We also publish results - regardless of outcome - in peer-reviewed journals or at scientific meetings. We publish the results of both successful and failed trials to advance scientific learning. Our medical writing follows industry standards, such as the Good Publication Practice guidelines (GPP3) published by the International Society for Medical Publication Professionals, and Recommendations for the Conduct, Reporting, Editing and Publication of Scholarly work in Medical Journals published by the International Committee of Medical Journal Editors. We also prepare plain language summaries of results to share with patients and the public. Additionally, we make reasonable efforts to address clinical data requests for legitimate medical/scientific research purposes from qualified researchers in the interest of improving patient care and helping advance medical science.

These collective efforts help patients access trial result information and facilitate compliant data

sharing with interested parties. For more information, see <u>Our Clinical Trial Transparency Commitment</u> and <u>Ultragenyx Clinical Trial Results.</u>

# In 2021, Ultragenyx:

- Published 13 peer-reviewed manuscripts
- Submitted over 100 abstracts
- Made over 125 oral and poster presentations at medical and scientific congresses

# Data Protection, Anonymization & Security During Clinical Trials

Ultragenyx is committed to high standards of integrity and compliance with applicable laws and regulations when handling patient data. Data from a clinical trial that is transferred to Ultragenyx is coded and does not contain names or other information that would make the participant identifiable. Trial participants must be informed if Ultragenyx examines their medical records. We require vendors supporting the trial to comply with applicable data protection laws and to have a data breach response plan in place. These measures are some of the ways that Ultragenyx works to protect the privacy and rights of our clinical trial participants. For more information on data protection and privacy, see Governance.

# Sharing Our Science & Expertise to Advance Drug Development

**Objective:** Foster industry-wide and community funded drug development efforts in rare and ultra-rare diseases

We are committed to helping the rare disease community by sharing our science and expertise to advance future drug development, whether by us or others.

- We share de-identified natural history data as well as endpoints, methods and validations we have developed with physicians, investigators and patient groups.
- We provide qualified researchers with legitimate medical/scientific research purposes access to data from our DMPs and clinical trials in the interest of improving patient care and helping advance medical science.
- We participate in several industry consortia and partnerships to foster and support collaborative, industry-wide drug development in rare and ultra rare diseases.
- We provide executive mentorship to rare disease families, advocates and foundations by sharing our expertise and providing drug development advice.

Additionally, we host a recurring RARE Entrepreneur Bootcamp, where we put our knowledge, expertise and connections to work to help patient families, foundations and other companies seeking to develop novel treatments for rare diseases. Our bootcamp is designed for patient families and advocates who have started funding their own rare disease research and are looking to better coordinate and build structure around their efforts. One prior bootcamp attendee went on to found GeneTx Biotherapeutics to treat Angelman syndrome, a disease with no approved therapy. We have since partnered with GeneTx to develop GTX-102, which is currently in a Phase 1/2 study.

# **Over 85 individuals**

representing more than 65 organizations have attended our **RARE Entrepreneur Bootcamp** since its inception in 2017.

# **Industry Participation**

- Member of the Angelman Biomarker and Outcome Measure Consortium (ABOM), which is developing an antisense oligonucleotide (ASO) for the treatment of Angelman syndrome, a serious, debilitating, rare neurogenetic disorder.
- Member of the LouLou Foundation CDKL5 Deficiency Disorder Consortium, which is directing the Clinical Assessment of NeuroDevelopmental measures In CDD (CANDID) study for the development of disease modifying therapeutics for CDD.
- Member of the Bespoke Gene Therapy Consortium, a
  first of-its-kind coalition between the public, private and
  nonprofit sectors to create a standardized approach to
  help reduce up front costs and lower barriers to
  developing new gene therapies for rare and ultra-rare
  diseases.
- Supporter of n-Lorem Foundation in bolstering its mission to bring immediate hope and rapid treatment to ultra rare disease patients.
- Supporter of Mereo BioPharma in delivering the "Living with Osteogenesis Imperfecta: Understanding Experiences Based on Community Insight and Experience" (IMPACT) Survey, a global gathering of data about the impacts on patients, their families and care givers of osteogenesis imperfecta (OI), a rare genetic condition that leads to abnormal bone structure, decreased bone mass, bone fragility and weakness.

# **IMPACT**

The greatest impact we can have on the lives of individuals with rare disease is to make our treatments accessible and affordable, and to engage and support rare disease families along every step of their journey.

# **Access & Affordability**

**Objective:** Achieve majority access through responsible pricing and support services

We believe that pricing should not be a barrier to accessing treatment and are committed to pricing our medicines responsibly. We set our drug prices with global pricing in mind and in the U.S., we use our best efforts to help ensure that no patient foregoes treatment for financial reasons. In addition, through global expanded access pathways, such as compassionate use, we are committed to honoring physicians' requests and providing therapies to patients in need where clinical trials are not feasible and therapies or indications have not yet been approved by local regulatory bodies.

# **UltraCare® Programs**

We created our UltraCare programs to help patients and caregivers understand their insurance coverage, determine eligibility for our financial assistance programs, navigate access to treatment and find patient support programs. UltraCare programs based on local regulations are currently in place in the U.S., Canada, Argentina, Brazil, Colombia and Mexico, and programs are in development in additional countries. Visit www.ultracaresupport.com for more information.

# **Compassionate Use**

We are committed to supporting patients and their families as they explore available treatment options following a rare disease diagnosis. In developing new medicines for children and adults with rare and ultra-rare diseases, we strive to make our investigational therapies available to patients through approved mechanisms, especially in countries where the treatments have not been approved by regulatory authorities.

While clinical trials provide access to our investigational therapies, some patients with a serious or life-threatening disease may not be eligible to participate in clinical studies and may not have other treatment options. In those cases, we seek to make our investigational therapies available on

# Over 380 patients in 43 countries

have been approved for access to Ultragenyx treatments through various global expanded access and patient assistance programs since 2013.

a compassionate use basis to qualified patients worldwide through our early access program. We evaluate requests for individual patients to receive investigational therapies outside of a clinical study on a case-by-case basis. The timeline of rare disease patients is urgent, so we endeavor to respond to compassionate use requests within 24 hours and to ship therapies within 48 hours where possible.



Similar to many rare diseases, there is no approved therapy for osteogenesis imperfecta (OI). OI causes bones to fracture easily and can also lead to bone deformities, pain, decreased mobility and short stature. Ultragenyx supported Mereo BioPharma in delivering a global gathering of data about the impacts of OI. Matthew, shown here, was diagnosed with OI at birth.

# Maintaining Access & Supply During COVID-19

For patients who rely on our medicines, we are committed to providing an uninterrupted supply and to continuing our efforts to expand access to our medicines for new patients. In 2020 and 2021, during the COVID-19 pandemic, we maintained a regular supply of both our medicines to patients around the world and our investigational treatments for patients in our clinical trials.

Early in the pandemic, we worked with the FDA to assist patients receiving Crysvita® in a clinical setting to transition to home administration. In May 2020, a temporary emergency authorization was granted for self-administration of Crysvita, one of the few therapies to receive this authorization.

# **Engagement & Support**

**Objective:** Use our expertise to amplify the voices of the rare disease community to inform and influence key decision makers in the field of rare disease

Listening to and connecting with patients is central to what we do. Ultragenyx was built from the ground up with rare disease community collaboration in mind. We partner with patients and their families from the earliest

stage of drug development through clinical research, and support patients and their families throughout the treatment life cycle. We also have the opportunity to listen to first-hand experiences from invited speakers living with rare disease, which allows us to see the real-world impact of the work we do for patients and families.

Ultragenyx has developed patient leadership councils to create ongoing relationships with advocates, caregivers and people living with rare disease, and to identify opportunities for potential collaboration. These councils meet regularly, and we seek longer-term memberships to maintain continuity in information sharing. Examples of councils include:

- LC-FAOD Patient Leadership Council
- XLH Patient Education Advisory Council
- Global Gene Therapy Advisory Council
- CTD Caregiver Leadership Council

The role of patient advocacy at Ultragenyx is to:

- 1) Educate by sharing information about rare and ultra-rare diseases and their impact.
- 2) Partner with patient organizations to support patients and caregivers.

- 3) Engage key policymakers to amplify the voices of the rare disease community.
- 4) Support patients, their families and the broader rare disease community through medical education and health-related grants.

# **Providing Educational Resources**

Our patient-focused websites provide customized education and rare disease awareness to patients and their families:

- www.ultrarareadvocacy.com
- <u>www.OneXLHvoice.pt</u> (available to the XLH community in Mexico and Brazil)
- www.mpsviiinfocus.com (available to the MPS VII community in English, Spanish, Portuguese, Italian, Polish, Romanian, Hungarian and Croatian)

Our Rare Journey Resources, available at <a href="https://www.ultrarareadvocacy.com">www.ultrarareadvocacy.com</a>, are designed to provide access to information for many of the common phases of the "rare" journey and empower patients and their caregivers to reach out and get involved.

We also prepare plain language summaries of clinical trial and DMP results to share with patients and the public. See <u>Clinical Trials</u> for more information.

## **Engaging Key Policymakers**

Policy and regulation are critical to the cost-effective and timely development and commercialization of treatments for the one in 10 Americans living with rare diseases. Our Global Policy Committee determines priority policy areas for our engagement and advocacy. The goal of the committee is to educate and inspire key decision makers in the field of rare disease with the aim of enabling all people living with a rare disease to receive an accurate diagnosis, care and available therapy as quickly as possible.

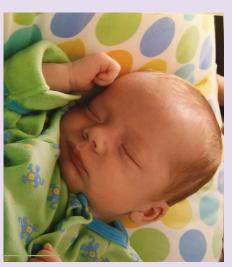
In 2021, we were a founding member of the Rare Disease Company Coalition, which educates policymakers on the distinct considerations of life science companies operating in the rare disease space.

Additionally, we amplify the voices of the rare disease community by supporting the following policy priorities:

- Extend life expectancy and improve quality of life for pediatric patients.
- Influence global advocacy initiatives of relevant rare disease patient organizations to raise awareness and provide access.
- Support efforts to streamline the regulatory process and establish innovative approaches for rare diseases and gene therapy to increase speed to market.
- Drive the development of methodologies that shorten the timeline from diagnosis to access to approval of therapies.
- Support efforts by patients, physicians and payers to remove barriers to access.
- Encourage a streamlined and expedited process facilitating timely reimbursement models.

## **Advocating for Newborn Screening**

Newborn screening is a vital part of treating rare diseases. With early detection, affected infants can receive prompt treatment that can help prevent permanent disability, developmental delay and death. Newborn Screening (NBS) programs in the U.S. are state-run public health programs that identify newborns with certain genetic, metabolic, hormonal or functional disorders. NBS programs are state run, which leads to major discrepancies in which states screen for which diseases. The number of total conditions screened for ranges from 32 to 67, and only one state - Pennsylvania - screens for all 35 core conditions and all 26 secondary conditions on the Recommended Uniform Screening Panel (RUSP). Ultragenyx advocates for these programs to screen for all conditions on the RUSP so that infants with rare disease can receive prompt access to treatment.



Christopher, born in 2008, was diagnosed with longchain L-3 hydroxyacyl-CoA dehydrogenase (LCHAD) deficiency thanks to newborn screening. People with LCHAD, a type of longchain fatty acid oxidation disorder (LC-FAOD), cannot break down longchain fatty acids and use them for energy. He has been on medication and a special diet since birth and is now an active teenager.

# Partnering with Patient Advocacy Groups

Ultragenyx works side by side with organizations that provide educational resources and support for those affected by rare diseases. We partner with the patient advocacy groups (PAGs) listed on our website to provide education, support and quarterly updates of our clinical programs. For example, in 2021, we hosted two town halls – one focused on Creatine Transporter Deficiency and one on CDKL5 Deficiency Disorder –that reached 220 participants.



Rahicy (left) and Ruan Veras Carvalo are siblings living in Piaui, a state in the northeast region of Brazil. Rahicy and Ruan are being treated with Mepsevii®, thanks to the support of the local patient advocacy group Associação Cearense dos Portadores de Doenças Raras (ACPDR). ACPDR has helped the family navigate the complex healthcare system, providing the family with renewed hope for their future. ACPDR receives financial support from Ultragenyx.

# Funding Independent Medical Education & Health-Related Grants

Ultragenyx provides independent medical educational and health-related grants to advance the medical and scientific understanding of rare and ultra-rare diseases, and to enable healthcare professionals to close clinical, research and other practice gaps. We make these annual grants with the ultimate purpose of improving care and increasing access to treatments.

Our funding is evaluated to maintain compliance with applicable requirements, including:

- The Accreditation Council for Continuing Medical Education (ACCME) Standards for Commercial Support (SCS).
- The American Medical Association (AMA) Ethical Guidelines for Gifts to Physicians from Industry.
- The FDA Guidance for Industry: Industry Supported Scientific and Educational Activities.
- PhRMA Code on Interactions with Healthcare Professionals.

# Over \$2.2 million

donated to over 100 rare disease patient advocacy groups in 18 countries in 2021

Ultragenyx also donates to nonprofit organizations that support communities where we live and work. See <u>Communities</u> for more information on our corporate philanthropy and volunteering efforts.

# People

Sustaining and strengthening our generous and inclusive culture and enhancing our health and safety practices

We are committed to maintaining a diverse, inclusive, safe and healthy environment, and to being a company where employees feel respected and valued. We are also committed to fair and equitable compensation practices that are transparent and free from bias.



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# **ASPIRATION:**

To be an inclusive, sought-after company where employees come first and feel motivated to bring the best versions of themselves to work each day, knowing they are making a difference in the lives of the rare disease community



### OBJECTIVES OUR PROGRESS

Maintain a turnover rate below our industry average

Support internal career and leadership development through our significant investment in customized employee programs that build skills and bring our culture to

Maintain a high employee engagement score

Continue to integrate inclusion and diversity considerations in succession planning, leadership nominations, and awards and promotions, to achieve and maintain gender balance and pay equity

Increase diversity in new hires through an intentional approach to awareness and education

Implement a robust and comprehensive health and safety management system framework and audit process Since 2020, Ultragenyx's voluntary turnover rate has been **less than 10%**, which is below the U.S. average for our industry (according to Aon Radford's Salary Increase and Turnover Studies).

- **80%** of employees attended at least one employee development workshop.
- **87%** of participants in the first two Cohorts of our leadership development program have been promoted within a year of completing the program.
- 13 interns hosted during our summer program.

Exceeded our objective to maintain a high score above 85% in our annual employee engagement survey.

- Diverse workforce with women **representing 58%** of our global workforce and 43% of our leadership positions at the VP level or above.
- 45% of U.S. employees self-report as members of diverse populations.

**Over 70% increase** from 2020 to 2021 in the number of new hires who self-reported as members of diverse populations.

While on the job:\*

- **Zero** lost time incidents.
- **Zero** serious injuries.
- Zero fatalities.

\*In accordance with the U.S. Occupational Safety & Health Administration (OSHA) standards

# **CULTURE & VALUES**

At Ultragenyx, we strive to create a culture where our people feel genuinely cared for and supported so that they can thrive in all areas of their lives. In 2021, over a quarter of new hires were made through our employee referral program. Ultimately, we want to be an organization where we are proud for our family, friends and children to work.

Our Cultural Values empower employees and show them their voices are heard and can make a difference.



### Generous

We are committed to helping - sharing our knowledge and skills with our patients, our field and each other.

### Courageous

We go where others won't - targeting untreated diseases and taking on the challenges that move our field forward.

### Possibility

We seek the undiscovered discoveries - we're committed to finding options for those who don't have any.

### Relentless

We won't give up fighting for our patients - together always searching for solutions.

### **Dynamic**

We learn and adapt - constantly searching for deeper understanding and rapidly evolving our plans based on our insights.

# HUMAN CAPITAL DEVELOPMENT

# **Objective:** Maintain a voluntary turnover rate below our industry average

Ultragenyx has over 1,100 employees globally. We are dedicated to fostering a workplace environment that keeps employees inspired and provides the vision, resources and support needed for success. This includes maintaining a healthy, inclusive company culture where employees feel respected and valued, and providing opportunities for learning, personal growth and career advancement. We strive to provide employees with a workplace and work environment where they do their best work and where they want to stay long term. In our most recent employee engagement survey, 94% of employees reported being proud to work at Ultragenyx.

Our executive leadership team plays an important role in workforce planning by periodically assessing the company's overall organizational design and structure. The goal is to identify future skills and capability needs, update leadership succession plans, and refine inclusion and diversity strategies.

We aim to conduct formal employee reviews twice per year and encourage managers to keep an ongoing dialogue with employees year-round to further support employee development. Additionally, managers meet regularly to discuss each employee to provide broader visibility of their strengths, career aspirations and performance contributions, and to identify opportunities to accelerate career development.

We also support and encourage team building with weekly company-sponsored lunches, group exercise, happy hours, milestone celebrations, summer and holiday events, and more. Many of these events have been held virtually since the COVID-19 pandemic began.

# Ultragenyx's voluntary turnover rate has been less than 10% since 2020,

which is **below the U.S. average** for our industry (according to Aon Radford's Salary Increase and Turnover Studies).



# **Employee Learning**

**Objective:** Support internal career and leadership development through our significant investment in customized employee programs that build skills and bring our culture to life

We value our employees and are invested in their personal and professional growth. Designed and delivered by a dedicated in-house team, our fit-for-purpose customized learning and employee development programs reinforce our values and build a specific set of skills and capabilities that brings our culture to life. Foundational to all our programs is deepening awareness and compassion of self and others, and fostering an inclusive and collaborative environment.

We offer a selection of both required and optional workshops. Required workshops include:

- Dynamic Feedback: Employees learn to seek, offer and receive feedback that is clear and kind and supports a dynamic culture of continual growth.
- Responsible Mindset: Employees learn how to recognize the powerful connection between mindset, actions and results. This empowers them to see choices and options that will lead to better, more fulfilling outcomes.

 Power + Privilege: Employees examine the many forms of power and privilege, such as role in the workplace, ethnicity, social economic status, education level and more. The workshop highlights how understanding power and privilege can foster individual growth and provides tools for using this knowledge to support others and cultivate allyship.

Additionally, we sponsor programs such as Ignite, a forum for exploring employees' unique and creative ideas, and UltraTalks, our version of TED Talks, designed to bring new perspectives and insights to the organization. These experiences build employee morale, stimulate innovation and invest employees in company improvement.

# 80% of employees

attended at least one employee development workshop in 2021.

# **Emerging Talent Programs**

As an advocate of early scientific careers, Ultragenyx is committed to providing emerging talent with a range of opportunities to learn from a diverse team of world-leading experts at the cutting edge of research. During the summer of 2021, we hosted 13 interns across Ultragenyx. In addition to working on specific projects, interns participated in fireside chats, panel discussions with leadership and final poster presentations. We are also actively developing additional emerging talent programs in cooperation with local universities and nonprofit organizations.



# **Employee Engagement**

# **Objective:** Maintain a high employee engagement score

We use the results of the "Your Voice" annual employee engagement survey to pinpoint focus areas and develop and enhance corporate policies. The survey is sent to employees who have been with Ultragenyx for at least 90 days. In 2021, our participation rate was 94%. Results of the survey are discussed with our board of directors and are used as part of the board's oversight of the general organizational health of the company.

Enhancing employee engagement is a corporate goal at Ultragenyx. A subset of the survey – focused on employee pride in our company, whether an employee would recommend Ultragenyx as a good place to work, if employees experience feeling a personal accomplishment from their work, and their intent to remain with us – is used to calculate an employee engagement score.

>85%

Employee Engagement Score in 2021

Beyond the engagement survey, team meetings are held regularly to enable interaction with senior leaders and managers. During these meetings, employees are encouraged to be inquisitive and data-driven so that decision making is responsive to inputs from employees.

# **Career Development**

In 2021, we piloted a new program to offer employees in our commercial organization access to on-demand career coaching services through an external network of professional executive coaches. The pilot ran for six months in North America, Europe and Latin America. Feedback from participants reflected positively on the ease of applying the coaching insights into their job performance. We are now working to expand this program.

We also invest in various training and development programs that build and strengthen our employees' leadership and professional skills. The goal of our Leadership Expansion & Development (LEAD) program is to build the next level of leaders that will help us evolve our organization and support our culture as we grow.

Started in 2018, each LEAD Cohort is cross functional, balanced geographically and inclusive of remote employees. The program uses workshops, business simulations, mentorship and executive leadership talks to equip participants with the skills to activate change throughout the organization. The LEAD program also seeks to empower a high-performing internal team to solve business and organizational challenges as well as to bring new ideas to the company. In the first two LEAD cohorts, 87% of participants were promoted within one year of completing the program.

# **2021 LEAD Cohort** Highlights

- **74%** women
- 11% based outside of the U.S.

# **INCLUSION & DIVERSITY**

**Objective:** Continue to integrate inclusion and diversity considerations in succession planning, leadership nominations, and awards and promotions, to achieve and maintain gender balance and pay equity

Ultragenyx is dedicated to maintaining a healthy and inclusive company where employees feel respected and valued and experience a sense of belonging from the start. Respect is a fundamental value that we require and expect from all our employees. This is core to our corporate culture and in alignment with our company goals to foster a thriving culture based on inclusion and diversity. Based on the results of our 2021 internal employee engagement survey, the vast majority of our employees reported feeling that executive leadership is committed to inclusion and diversity.in company improvement.

Total Number of Global Employees	1,118
Proportion of women	58%
Total Number of U.S. Employees	1,016
Proportion of women	59%
Proportion of U.S. employees who self-report as members of diverse populations**	44%
Proportion of women in U.S. leadership positions (VP and above)	44%
Total Number of Members on Ultragenyx's Executive Management Team	9
Number of women on the executive management team	3
Executive management team who self-report as members of diverse populations**	3

<sup>\*</sup> As of December 31, 2021. U.S. employee data is consistent with our submission on the U.S. Federal Employer Information Report Equal Opportunity (EEO-1) Form.

We have taken several steps to bolster inclusion and diversity (I&D) within our company.

# Highlights of our accomplishments include the following:

- Formed an I&D action team comprised of I&D champions across the company to lead our program and began recruiting for an I&D leader to expand our efforts.
- Added diversity analysis as part of the succession planning process.
- Hosted our first I&D Summit for our employees to expand our understanding of I&D and explore how we can deepen our I&D journey.
   Nine sessions were held over three days, with attendance at each session ranging from 150 to 300 employees.
- Fostered dialogue and engagement through our internal employee resource groups and launched two new groups, UltraMosaic and LatinX.
- Began providing resources and education on gender identity for employees to increase our collective awareness of issues facing the transgender community as well as provide guidance on how to be an informed and active ally.

<sup>\*\*</sup> Based on employees self-reporting race and ethnicity

# **I&D Employee Resource Groups**

I&D employee resource groups (ERGs) are voluntary, employee-led groups that aim to foster a diverse and inclusive workplace. In 2021, Ultragenyx welcomed two new I&D ERGs, UltraMosaic and LatinX.



Creating a supportive culture to encourage women, diversity and equality in leadership and science.



Promoting diversity and increasing the visibility of LGBTQ+ employees, raising cultural awareness and ensuring an inclusive environment to enable all employees to flourish and do their best work.



A mix of ethnic groups and cultures that coexist within society and here at Ultragenyx – recognizing and celebrating our uniqueness and using our gifts, abilities and resources to support one another and the company.



Empowering the LatinX community at Ultragenyx to realize its fullest potential and encouraging the next generation of LatinX talent to pursue careers in science and biotechnology.



Our X-tended Office ERG seeks to enhance Ultragenyx's remote working experience to ensure that during the pandemic, while so many worked from home, employees still felt a sense of belonging.

### **Rare Pearl Award**

The Rare Pearl Spotlight Award is presented annually by the X2 Women in Biotech ERG to employees who exemplify Ultragenyx's culture and values while working on a project or activity that enriches the company's culture of inclusion and diversity. The winners for 2021 exemplified our inclusive and diverse culture, showing respect and kindness for others and going beyond their expected job duties.



# **HBA Luminary Award**

Camille Bedrosian, MD, Ultragenyx's chief medical officer, was recognized with a 2021 HBA Luminary Award from Healthcare Businesswomen's Association (HBA). Luminaries are identified by their companies for serving as a role model, actively mentoring and sponsoring others, helping advance other women's careers and exhibiting dedication to the healthcare industry.



# **I&D** in Recruitment

# **Objective:** Increase diversity in new hires through an intentional approach to awareness and education

We adopted an intentional approach to recruitment that focuses on creating a welcoming and positive experience for each candidate. We aim to create a sense of belonging from the very start to foster an inclusive workforce.

Our intention is to create a diverse pipeline of candidates applying for jobs at Ultragenyx by using strategies such as diverse interview teams to "screen in" instead of "out" to mitigate bias. Additionally, we:

- Host virtual open houses and career fairs to support our broad outreach efforts.
- Launched a new job posting tool, which supports more equitable job posts by reducing overall job post length, matching job title to external candidate searches and removing exclusionary language.
- Provide interview skills training to our employees
  to support inclusive interviewing and a deepened
  understanding of unconscious bias, which can
  create barriers for those who are underrepresented
  in the workforce.

Through our intentional approach, we have seen an increase in the number of diverse candidates interviewing for potential employment as well as the number of new hires who self-report as members of diverse populations.

# More than a 70% increase

between 2020 and 2021 in the number of new hires who self-reported as members of diverse populations



During his keynote address at our National Sales Network (NSN) conference, Chief Commercial Officer Erik Harris (pictured) announced that his family **established an NSN scholarship to support opportunities for diverse candidates.** Ultragenyx is proud to match the family's contribution to double the impact. The new scholarship honors Erik's father, Dave Harris Sr., one of the first African American pharmaceutical sales representatives. Dave has served as a mentor and ally for people from diverse backgrounds who aspire to work and grow their careers in the pharmaceutical industry.

# **I&D in Recruitment at Our New Gene Therapy Manufacturing Facility**

Our new gene therapy manufacturing facility is under construction in Massachusetts. We have integrated I&D considerations into the recruitment process from the beginning to foster an inclusive workforce and to support diverse candidates. Efforts include:

- Conducting outreach to diverse associations to develop connections, post jobs and advertise virtual career fairs.
- Introducing cultural awareness into our interview skills workshop.
- Removing names from resumes to reduce unconscious bias in interviewing.

For more information about this facility, see <u>Planet.</u>

# OCCUPATIONAL HEALTH, SAFETY & WELLNESS

Objective: Implement a robust and comprehensive health and safety management system framework and audit process

The health and safety of our workforce is a key priority. Our health and safety management system is vital to a safe and healthy work environment. The system is based on the principles of ISO 45001:2018, the International Organization for Standardization (ISO) standard for occupational health and safety management, and is designed to:

- Comply with applicable statutory and regulatory requirements and Ultragenyx policies.
- Proactively identify and prioritize occupational health and safety risks and potential mitigation options for our operations.
- Maintain effective emergency response preparedness.
- Drive continuous improvement across our operations.

Our health and safety training program is administered through several formats, such as instructor-led training, documented standard operating procedures, risk assessments, job safety analyses and hazard identification. As part of onboarding and orientation,

our workforce receives this training, which also includes information on emergency response, hazard communication, ergonomics, electrical safety, evacuation, fire, medical procedures and specific information pertaining to safety. Additionally, all laboratory employees receive chemical safety and biosafety/bloodborne pathogen safety training and are required to attend refresher training annually.

In 2022, we plan to launch an enterprise-wide safety council led by our chief quality operations officer to evaluate and mitigate safety risks. The council is expected to oversee site-level safety committees and manage regulatory compliance, safety program, audits and corrective actions.

In 2021, Ultragenyx had zero lost-time incidents, zero serious injuries and zero fatalities of employees, contractors, and contingent and termporary workers while on the job, calculated in accordance with the U.S. Occupational Safety and Health Administration and excluding third-party manufacturing.

# **Our Response to COVID-19**

During the last 24 months, most of our employees worked remotely. For those who remained inoffice, we took measures to create and maintain a safe work environment. Our policy is to follow the recommendations and guidelines put forth by the Centers for Disease Control (CDC) and we have taken additional measures, such as upgrading heating, ventilation and air conditioning (HVAC) systems, installing automatic faucets and touchless door openers, conducting weekly polymerase chain reaction (PCR) testing for employees, and requiring vaccinations for our U.S. workforce (unless exempted where allowed by law).

Toward the end of 2021, we defined a new work model that reimagines the role of the physical workspace to create a flexible hybrid environment where individuals can do their best work. Some of our employees will remain fully remote, while other will either spend two or three days per week in office or return to fully office-based.

# Wellness

We provide our employees with wellness offerings to support their physical and mental health.

- Spring Health offers mental wellness screening, stress management, coaching, and up to four free virtual therapy sessions and two free psychiatry sessions each year to employees and covered dependents.
- Mindfulness and Meditation programs as well as informal support groups are available to employees struggling during the pandemic with caregiving, isolation and stress.
- Annual Flu Shot Clinics are available in offices. Flu shots are covered for free in the U.S. for employees plus family members and are reimbursed for employees and their family members outside the U.S.
- Caregiving and Fitness Reimbursements cover fitness classes and gym membership, nanny and childcare, backup childcare, summer camp, eldercare services, meal delivery service to a dependent family member and pet walking.
- UltraReboot Program encourages employees to Take time off in the summer to re-energize.

- Access to a Personal Health Advocate is available to assist our U.S. employees and their families with navigating the healthcare system and maximizing benefits.
- Ergonomics Assessments are offered to help employees adjust their workstations and equipment for long-term comfort and physical health.



# **Employee Compensation & Benefits**

Ultragenyx employees bring their best to work every day and we honor their dedication by offering competitive compensation and benefits packages designed to attract, retain and motivate talented people. We are committed to fair and equitable compensation practices within a payfor-performance framework and believe these principles are critical in supporting our culture and achieving our mission. We regularly review our programs and practices as well as our employees' pay with the goal of providing pay and opportunities that are equitable, transparent and free from bias. Our compensation decisions are based on role, performance, location, external and internal peer data, relevant experience, professional and personal contributions, and senior leadership review.

Our benefit programs provide employees and their families with access to a suite of innovative programs that enhance their physical, emotional, familial, financial and social well-being. Our programs include a comprehensive selection of medical, dental and vision plans, retirement savings options, competitive paid time off and many other programs that support balancing work with life. Eligible employees participate in our annual short-term and equity-based long-term incentive programs, which provide opportunities to share in our company's success. More information can be found on our <u>Careers</u> webpage.

# Communities

Aligning our corporate philanthropic efforts with our mission and purpose

We are committed to building stronger and healthier communities by being a thoughtful and responsible neighbor, providing jobs, and supporting educational, humanitarian, and public health and wellness initiatives.





# **ASPIRATION:**

To make a positive impact in the communities where we operate and beyond



# **OBJECTIVES** organizations. Support charitable organizations that contribute meaningfully to the health and well-being of the communities

Stimulate the economy, provide jobs to local residents and address community needs

where we operate and beyond

### **OUR PROGRESS**

- Donated over \$130,000 to 11 community-based or rare-disease focused
- Employee donations supported:
  - o 76 families at the San Francisco chapter of Homeward Bound, a provider of shelters and services for homeless families and individuals.
  - o 150 children through the Wonderfund Holiday Gift Drive in partnership with the Massachusetts Department of Family and Children's Services.
  - o 150 children through Guardiões da Esperança (Guardians of Hope) in Brazil.
- Extended the number of volunteer days for employees with medical licenses, certifications and/or training so that they can volunteer their time to local hospitals where COVID-19 first response efforts are needed.
- Donated over \$335,000 in lunches and snacks through local small catering businesses to first responders and at-risk communities in the Boston and San Francisco areas in 2020 and 2021 to support them during the COVID pandemic
- > 850 employees, about 1,200 vendors and contractors, and 23 clinical trial sites in the eight states with our largest presence.

# **CORPORATE GIVING**

**Objective:** Support charitable organizations that contribute meaningfully to the health and wellbeing of the communities where we operate and beyond

Our corporate giving focuses on providing food, shelter and services to those in need; fostering education in math, engineering and science as well as support for those pursuing careers in the life sciences; and supporting people who are undergoing treatment for serious and life-threatening diseases. These donations are in addition to the funding Ultragenyx provides for medical education and to support patient advocacy.

# 2021 Corporate Giving Highlights

- Donated over \$130,000 to 11 community-based or rare-disease focused organizations.
- Partnered with Life Science Cares to provide volunteer opportunities to Ultragenyx employees in support of local public health and wellness initiatives in the San Francisco Bay and Greater Boston areas.

- Donated to Biotech Partners to support students interested in science, technology, engineering and math (STEM) careers.
- Continued our long-standing support of North Marin Community Services, a nonprofit organization that provides integrated and culturally appropriate services to people in need in northern Marin County, California.
- Donated to nonprofit organizations that support children and families in need within our communities, such as Homeward Bound, Ritter Center, San Francisco-Marin Food Bank, Sparkle Foundation and Wonderfund.

# **Over \$335,000 donated**

in meals and snacks to pandemic first responders and at-risk communities during 2020 and 2021



Ultragenyx supported **Heroes and Helpers** in 2021, a partnership between North Marin Community Services and the Novato Police Department that enabled 60 children from low-income families to purchase holiday presents for their siblings and other family members.

Photography by Penny Hansen Rotary Club of Novato



In 2021, Ultragenyx supported **Little Wishes™**, a nonprofit organization that grants wishes to chronically and critically ill, hospitalized children to ease their discomfort, bring them moments of joy and brighten long hospital stays. Pictured here is Daniel, a 13-year-old awaiting a heart transplant at Arkansas Children's Hospital, who wished for a guitar.

#### PAID VOLUNTEER TIME

Ultragenyx offers employees the opportunity to take two paid volunteer days each year (16 hours), so that they can spend time giving back to our communities and contribute to local initiatives. In 2021, employees logged hours for numerous volunteer activities, including repairing nature trails, working at local food banks, supporting holiday gift drives, building science kits and working at vaccination clinics.

In response to the continuing impacts of the COVID-19 pandemic around the globe, we extended the number of volunteer days for employees with medical licenses, certifications and/or training so that they can volunteer their time to local hospitals where COVID-19 first response efforts are needed. This includes support of vaccination efforts within our communities.



Megan Bell, a member of our market access team and a registered nurse, joined the Swedish Medical Group's initiative to provide immunizations for COVID-19 in Seattle.

Megan provided first-dose vaccinations to nearly 100 community members and volunteered again to give second doses.

# EMPLOYEE GIVING & VOLUNTEERING

UltraGiving is an ERG committed to connecting employees with opportunities to support nonprofit organizations assisting underserved communities. Once the connections are made, employees can choose to use their paid volunteer time, volunteer on their own or make donations. In some cases, the organizations are the same as those supported by corporate giving; in others, employees identify different organizations they wish to support. UltraGiving has chapters in the San Francisco Bay and Greater Boston areas and added new chapters in Utah and Brazil in 2021. Ultragenyx employees also volunteered their time to serve on the boards of directors for local nonprofits, such as North Marin Community Services, Life Science Cares and the Novato Chamber of Commerce.

#### \$9,800 raised

by the San Francisco and Boston chapters to support end-of-the-year **food drives.** 

# Over 75 families supported

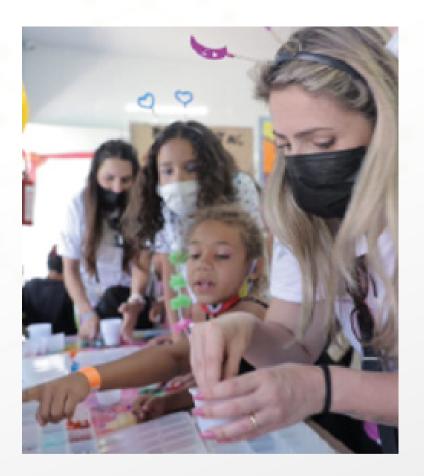
with \$3,800 in donations from the San Francisco chapter of **Homeward Bound**, a provider of shelters and services for homeless families and individuals.

# 150 children received gifts

through the **Wonderfund Holiday Gift Drive** in partnership with the Massachusetts Department of Family and Children's Services, supported from the Boston Chapter's donations.

#### 150 children supported

with more than \$8,000 in donations and volunteer time from the Brazil chapter of **Guardiões da Esperança** (Guardians of Hope).

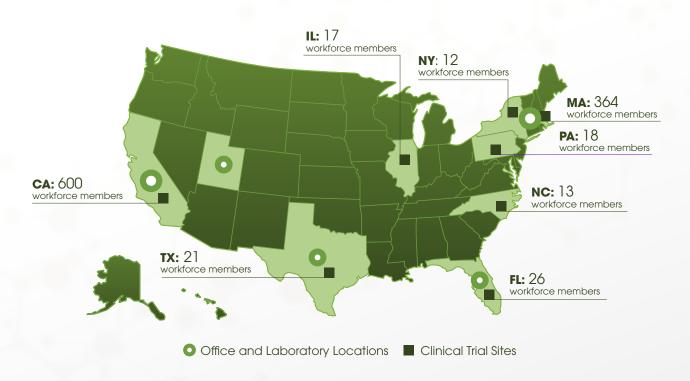


# SUPPORTING LOCAL ECONOMIES

# **Objective:** Stimulate the economy, provide jobs to local residents and address community needs

In addition to hiring talented life science professionals from the communities in which our facilities are located, we also support hundreds of local contractors and vendors. In the eight states with our largest presence in the U.S., we have 886 employees, 1,200 contractors and vendors, and 23 clinical trial sites.

#### LOCAL ECONOMIC IMPACT



Ultragenyx has a global footprint. Here, we list eight states where we have the largest impact in the U.S. on economic opportunity and support of local rare disease communities (based on 2021 data):

#### California

- 500 employees
- 100 contractors
- 375 vendors
- 8 clinical trial sites

#### Florida

- 26 employees
- 37 vendors
- 3 clinical trial sites

#### Illinois

- 17 employees
- 129 vendors
- 2 clinical trial sites

#### Massachusetts

- 279 employees
- 85 contractors
- 192 vendors
- 1 clinical trial site

#### **New York**

- 12 employees
- 81 vendors
- 2 clinical trial sites

#### North Carolina

- 13 employees
- 28 vendors
- 1 clinical trial site

#### Pennsylvania

- 18 employees
- 95 vendors
- 2 clinical trial sites

#### Texas

- 21 employees
- 78 vendors
- 4 clinical trial sites

Employees work remotely in states where we do not have offices or labs.

# Planet

Reducing our environmental impact across our business

We are committed to developing an environmental strategy that recognizes our contributions to the health of the planet and minimizes our environmental footprint across our business.





#### **ASPIRATION:**

To conduct business in an environmentally responsible manner and strive to continuously improve our performance to benefit our employees, customers, communities and the environment



OBJECTIVES	OUR PROGRESS		
Implement continuous improvements to reduce our environmental footprint	<ul> <li>Purchased 100% renewable electricity for our Novato, California, headquarters campus.</li> <li>Installed electric vehicle charging stations at our California offices in Novato and Brisbane, with plans to install more at our new gene therapy manufacturing facility in Massachusetts, scheduled to open in 2023.</li> <li>Piloted sustainable building design standards at the new gene therapy manufacturing facility in Massachusetts.</li> <li>Began recycling emptied plastic pipette tip boxes with a third party that remanufactures the plastic into new plastic pipette tip boxes.</li> </ul>		
Develop an environmental strategy	<ul> <li>In 2022, Ultragenyx plans to begin collecting environmental data across its office and laboratory spaces – on greenhouse gas (GHG) emissions, energy consumption, waste and water – as our initial step toward developing an environmental strategy.</li> </ul>		

## REDUCING OUR ENVIRONMENTAL FOOTPRINT

# **Objective:** Implement continuous improvements to reduce our environmental footprint

As we look to advance a diverse portfolio of novel treatments in rare and ultra-rare diseases, Ultragenyx is working to reduce the environmental impact of our business by enhancing and promoting sustainable practices across our office and laboratory spaces, whether leased or owned, and designing our future spaces and gene therapy manufacturing facility with sustainability in mind. To date, we have completed a number of improvements, such as:

- Converting to LED lighting systems in all common areas.
- Replacing HVAC systems with more energyefficient models.
- Programming HVAC equipment for setbacks during off hours.
- Installing building management systems, which allow for improved energy efficiency in our use of lighting, heating and cooling.
- Replacing the main passenger elevators with higher efficiency models.

- Upgrading common area sinks and toilets to low flow units to conserve water.
- Implementing a single-stream recycling program.
- Installing water dispensers to reduce purchases of single-use plastic bottles.

Ultragenyx is committed to protecting and respecting the environment and that commitment extends to our supply chain. We expect our suppliers to follow applicable environmental laws, regulations and standards, including those concerning chemical and waste management, recycling, industrial wastewater treatment and discharge, air emissions controls, environmental permits and environmental reporting.

We expect our suppliers, wherever possible, to support a precautionary approach to environmental matters, undertake initiatives to promote greater environmental responsibility, and encourage environmentally preferable technologies and sound life-cycle practices. These expectations are laid out in the Ultragenyx Standard for Suppliers.

#### **Managing Waste**

Our policy is to comply with applicable federal, state and local requirements for the handling of hazardous and non-hazardous wastes. We have procedures in place, along with training and compliance audits, to promote appropriate handling and disposal of these waste streams.

We also look for opportunities to recycle waste. With the help of a third party, Ultragenyx is using a closed-loop mail-back program to return emptied pipette tip boxes to a processing facility for remanufacturing. Instead of this non-renewable material being discarded as waste, it becomes part of a closed-loop system and is recycled into new pipette tip boxes time and again. This solution can extend the life cycle of scientific materials, which supports both a circular economy and a reduction in our indirect carbon footprint.



#### **Carbon Footprint**

Ultragenyx has introduced several initiatives to reduce the company's carbon footprint.

• In 2021, our headquarters in Novato, California, began purchasing 100% renewable electricity through Marin Clean Energy's Deep Green program. Through the program, we are purchasing Green-e® certified renewable electricity from solar and wind sources and eliminating greenhouse gas (GHG) emissions associated with our electricity use. Purchasing renewable electricity supports the City of Novato's Climate Change Action Plan, which outlines strategies for the city to achieve a GHG reduction target of 40% below 2005 levels by 2035.



- Electric vehicle (EV) charging stations are offered at the Novato and Brisbane, California, office complexes to support employees who drive electric vehicles. Each campus has 10 EV charging ports, including two that comply with the Americans with Disabilities Act. EV charging is also planned for our new gene therapy manufacturing facility that is under construction in Massachusetts.
- Ultragenyx offers several public transportation reimbursement benefits to our employees around the world to encourage utilization of public transportation. We also plan to install a bike rack and a bus stop for the Massachusetts Transit Bus line at the new gene therapy manufacturing facility in Massachusetts to encourage alternate means of commuting. Taking public transportation to and from work reduces the number of vehicles on the roads, which in turn reduces GHG emissions from employee commuting.

#### LOOKING AHEAD

### **Objective:** Develop an environmental strategy

In 2022, as part of our commitment to minimizing our environmental footprint, Ultragenyx plans to begin collecting environmental data – on greenhouse gas (GHG) emissions, energy consumption, waste and water – as an initial step toward developing an environmental strategy. The scope of the strategy is expected to cover our activities at both existing laboratory and office locations. In the future, the scope is expected to further extend to cover our supply chain.

# SUSTAINABLE BUILDING DESIGN AT OUR GENE THERAPY MANUFACTURING PLANT

We have a robust clinical pipeline of gene therapies. With our clonal Producer Cell Line (PCL) technology, we have established a new manufacturing system that can produce adeno-associated virus (AAV) vectors with increased efficiency and lower material costs than most traditional methods, and at a scale that could help meet the rising demands of today's gene therapy landscape. We are building a gene therapy manufacturing facility in Bedford, Massachusetts, to provide us with the flexibility and control of process that can further optimize the clonal PCL platform.

Ultragenyx established a set of sustainable building design standards that were piloted at our new gene therapy manufacturing facility, which is currently expected to open in 2023.



# Energy Efficiency & GHG Emissions Reductions

As part of constructing our new gene therapy manufacturing facility, Ultragenyx is participating in Mass Save®, an incentive program sponsored by electric utilities, under the "Whole Buildings Streamlined" path. The program evaluates energy savings by comparing the facility's design features to a baseline based on the state's current energy code. The design of our new site, which will house manufacturing, laboratory and office space, includes numerous energy conservation measures that go beyond the current energy code, such as:

- LED lighting and lighting occupancy sensors.
- High efficiency uninterrupted power supply system.
- High performance condensing boilers and chillers.
- Dewpoint controlled air dryers.
- Demand control ventilation.
- Unitary HVAC system.
- Low-flow domestic hot water fixtures.

When all of the planned measures are implemented, we expect to save more than **550,000 kWh** annually at our manufacturing facility. These energy savings are equivalent to avoiding the emissions from driving over 1 million miles by an average passenger vehicle or the annual emissions from energy used to power about 50 homes.

#### **Air Quality**

Beyond energy efficiency, our teams work to improve air quality. A large emergency power diesel generator is required as a backup power source so that there is no disruption to manufacturing and supply of investigational therapies. Currently, the state of Massachusetts allows the exhaust from these units to be discharged directly to the environment as long as the exhaust stack meets minimum height requirements. We have voluntarily incorporated the use of selective catalytic reduction to significantly reduce the amount of nitrogen oxide (NOx) emissions generated by the units.

For more information about this facility, please see <u>Inclusion & Diversity.</u>

# 45% reduction in NOx emissions

because of our use of selective catalytic reduction on the emergency power generator at our new gene therapy manufacturing facility Governance

Maintaining robust corporate governance and risk management and upholding the highest standards of honest and ethical business conduct

The foundation of our purpose to lead the future of rare disease medicine is built upon our commitments to:

- Strong corporate governance structures at both the board and company leadership levels.
- Upholding the highest standards of ethics and integrity.
- Compliance with applicable laws and regulations.
- Data protection and security.
- Responsible procurement.





#### **ASPIRATION:**

Through strong corporate governance and a culture of integrity, prevent significant issues before they occur and foster an environment where issues are disclosed without the threat of retaliation. If and when issues arise, our policy is to thoroughly investigate to identify root causes and, in a timely and efficient manner, implement measures to stop repeat occurrences.



#### OBJECTIVES OUR PROGRESS

Act responsibly and with integrity and provide annual, targeted training to full-time and contingent workers on Ultragenyx's ethical standards

Maintain a high compliance culture and adherence to all applicable legal requirements

Maintain a high rate of thirdparty due diligence of our suppliers

- All employees are required to sign an acknowledgement of receipt and understanding of the Ultragenyx Code of Conduct on an annual basis.
- We provide ethics training to all employees and contingent workers.
- Our compliance program is led by our chief compliance officer with oversight from the compliance committee, which provides guidance on global healthcare laws and regulations and has direct reporting responsibilities to the board and CEO.
- We have consolidated information security and cyber resiliency activities under the leadership of our director of information security and chief information officer.
- Our Standard for Suppliers and supplier due diligence process help us engage with third parties that share our values and our commitment to ethics and compliance.

#### CORPORATE GOVERNANCE

We believe that good corporate governance promotes the long-term interests of our stockholders and other stakeholders. We are committed to maintaining good corporate governance practices and we periodically review our practices.

Our Global Code of Conduct (Code) establishes principles and expectations that apply globally to all employees, officers and directors regardless of position or tenure. Our corporate governance guidelines serve as a framework for conducting the board's business and assist the board in the exercise of its duties and responsibilities to serve the best interests of Ultragenyx and its stockholders.

#### **Board of Directors**

The board of directors (the board) provides us with strategic guidance as we work to advance our mission of making a meaningful difference in the lives of patients with rare genetic diseases. Our board is comprised of experienced leaders that represent a diversity of talents, skills, backgrounds and expertise.

Our board currently has a standing Audit Committee, Compensation Committee, Nominating and Governance Committee, and Research and Development Committee. Each of these committees operates under a written charter setting forth the functions and responsibilities of the committee, a copy of which is available on <u>our website.</u>

For more information on our directors and corporate governance, please see our <u>Proxy Statement.</u>
See also <u>ESG Strategy</u> for information on our ESG governance approach.

#### **Board Diversity**

- Three are women
- **Two** self-identify as Asian
- One self-identifies as LGBTQ+
- Average age of 62.7 years
- Average tenure of 6.7 years

As of April 1, 2022, our board consisted of nine members.

#### **Best Practices**

Ongoing shareholder engagement program

Diverse board

Board oversight of ESG

Minimum stock ownership requirements for directors and named executive officers

100% attendance of board and committee meetings in 2021 by our current directors

Director Overboarding Policy

#### Independence

Strong and active independent board chairman

Other than our president and CEO, all other directors are independent

100% independent directors in Audit Committee, Nominating and Corporate Governance Committee and Compensation Committee

#### **Accountability**

Director Resignation Policy for directors that receive less than majority support in uncontested elections

Clawback Policy

Annual board and committee self-evaluations

Prohibition against hedging transactions

#### **Risk Management**

Ultragenyx's board has overall responsibility for the oversight of our risk management process, which is designed to support the achievement of organizational and strategic objectives to improve long-term organizational performance and enhance stockholder value.

The board periodically reviews our business strategy and management's assessment of the related risk and discusses with management the appropriate level of risk for the company. In 2021, the board and the committees reviewed with management various risks and mitigation strategies, including those related to:

- The COVID-19 pandemic, such as the company's return to work and vaccination policies.
- The company's initiatives related to ESG and sustainability matters.
- Cybersecurity and security programs related to our information technology systems.
- Human capital management, such as employee retention and recruitment.
- The continued appropriateness of the company's classified board and other structural elements of the company.
- The company's approach to evaluating its clinical and preclinical programs.

The board delegates oversight of certain risks to each board committee, and each member of the executive leadership team is responsible for certain risk areas. Executive leadership is responsible for establishing our

business strategy, identifying and assessing the related risks, and implementing appropriate risk management practices. For a summary of risks and uncertainties, see Item 1A Risk Factors in our 2021 Annual Report.

#### **Risk Management Oversight**

The board of directors, its committees and Ultragenyx's executive leadership team oversee the company's risk management program, which includes periodic reporting and open lines of communication.

#### **Board of Directors**

Has overall responsibility for the oversight of risk management

#### Executive Leadership Team Is responsible for establishing our business

strategy, identifying and assessing risks, and implementing appropriate risk management practices

#### **Board Committees**

## Nominating and Corporate Governance

Oversees risks related to board composition, evaluation and succession planning, ESG and sustainability, and compliance

#### Compensation

Oversees risks related to human capital, including compensation, senior management succession planning, inclusion and diversity, and pay equity matters

#### Audit

Oversees risks related to financial, data privacy and cybersecurity

#### Research and Development

Oversees risks related to company's pipeline, investment and R&D activities

#### **ETHICS & INTEGRITY**

Objective: Act responsibly and with integrity and provide annual, targeted training to full-time and contingent workers on Ultragenyx's ethical standards

Ultragenyx is committed to maintaining high standards of honest and ethical business conduct. We have policies designed to prevent, deter and detect bribery, fraud and other corrupt business practices. In 2021, Ultragenyx did not have any material monetary losses as a result of legal proceedings associated with corruption and bribery (please refer to our 2021 Annual Report).

Our <u>Global Code of Conduct</u> (Code) establishes principles and expectations that apply globally to our workforce, officers and directors regardless of position or tenure. The Code sets expectations on ethical decision-making and covers a variety of topics, such as equal employment opportunity, anti-discrimination and anti-harassment, anti-bribery and anti-corruption, and anti-trust and competition laws. The Code also makes clear when and how individuals should raise concerns and documents our no-retaliation policy. We enforce our policies and requirements with appropriate disciplinary actions, when necessary, and we take a zero-tolerance approach to any violation of law or policy.

The company reinforces compliance with the Code's expectations through training that we provide to our employees. Additionally, all U.S.based employees must acknowledge our antiharassment and anti-discrimination policy and complete the company-offered training within the first several months of employment. All U.S. employees, including part-time and temporary employees, must take a harassment prevention training course every year. If an employee makes a complaint of discrimination or harassment, Ultragenyx's policy is to conduct a timely and thorough investigation and take appropriate action. Investigations are assessed and conducted based on Ultragenyx's internal investigations protocol and are typically conducted by the company's employee relations department.

#### **Ethical Treatment of Animals**

Ultragenyx is committed to the ethical treatment of animals used in the development of potential new and life-changing therapies for patients with rare disease. Our company is committed to the "3Rs":

- Replace Use non-animal methods for experiments whenever possible, such as simulations and computational tools or in vitro systems.
- Reduce Use the minimum number of animals in each study in order to achieve valid results and objectives.
- Refine Use procedures that decrease the potential for pain and limit distress for animals.

We expect external service providers to meet or exceed all animal care and use standards that are applicable to local and national laws and regulations. Our external service providers are accredited by the American Association for Accreditation of Laboratory Animal Care (AAALAC), a private, nonprofit organization that promotes the humane treatment of animals in science through voluntary accreditation and assessment programs. Additionally, animal facilities are governed by an Institutional Animal Care and Use Committee (IACUC), which oversees all aspects of animal care, welfare and scientific programs for research. The IACUC reviews all animal use protocols, oversees compliance with federal regulations, inspects animal facilities, and manages animal handling/training and educational programs.

#### **COMPLIANCE PROGRAM**

# **Objective:** Maintain a high compliance culture and adherence to applicable legal requirements

We maintain a high compliance culture by demanding ethical behavior, holding each individual accountable for compliance, fostering effective communication and working together to make good decisions. We comply with applicable laws and regulations while maintaining patient safety and leadership accountability. Our comprehensive program has been developed in accordance with the laws applicable to our industry, the Program Guidance for Pharmaceutical Manufacturers published by the Office of the Inspector General of the U.S. Department of Health and Human Services, and the PhRMA Code of Interactions with Healthcare Professionals.

Ultragenyx's compliance program includes:

- A compliance officer and compliance committee responsible for developing, operating and monitoring the compliance program and with authority to report directly to the board and our CEO.
- Written standards of conduct, policies and practices that document the company's commitment to compliance and requirements to strictly follow fraud and abuse laws.

- Easy to understand, effective and readily available education and training programs for all employees. On an annual basis, employees are expected receive and acknowledge understanding of the Ultragenyx Code of Conduct.
- Open lines of communication and partnership between the compliance officer and workforce to ethically achieve our company mission and goals.
- Continued enhancement of an audit and monitoring program to identify and address risks.
- Enforcement of compliance obligations through guidelines that include disciplinary action for noncompliance.
- Mechanisms to promptly and properly investigate and respond to reports of noncompliance, including processes to initiate corrective measures.

#### **Compliance Hotline**

Ultragenyx's compliance hotline, which also serves as the Confidential and Anonymous Financial Concern Hotline, allows employees or anyone else to report any potential or actual violations of Ultragenyx's Code of Conduct, company policies and procedures, and applicable laws and regulations. Any employee can provide comments using the hotline. Messages may be submitted anonymously using a secure web form, email or telephone.

Complaints or other messages left on the compliance hotline are anonymously sent to our chief legal officer and the chairperson of our Audit Committee, who then take the necessary next steps.

#### Interactions with Patients, Caregivers & Healthcare Professionals

We respect the doctor-patient relationship and the privacy rights of patients, and we strive to interact with patients and caregivers in an appropriate manner and in compliance with applicable laws and regulations as well as our internal healthcare compliance manual. Ultragenyx has adopted policies and practices consistent with the PhRMA Code and other applicable industry standards that govern interactions with healthcare professionals. These policies include:

- Support for medical education as well as the use of healthcare professionals to provide services to the company as researchers, consultants and speakers.
- Provision of business courtesies.
- Making of grants and charitable contributions so that such funds are not conditioned, expressly or implied, on any agreement to prescribe, purchase, recommend, influence or provide favorable formulary status for any Ultragenyx product.

 Promotion of Ultragenyx products in compliance with the FDA 's regulatory framework as well as regulatory requirements in other jurisdictions regarding promotion of pharmaceutical products.

Our compliance program with the oversight of a management-level compliance committee provides guidance with respect to healthcare law compliance. The committee meets at least quarterly.

#### DATA PROTECTION & PRIVACY

We are committed to compliance with all global privacy laws and maintain a privacy program, including a global privacy policy, comprehensive training, and system operating procedures and controls. We expect our workforce to be accountable, to protect personal data, which we may acquire or maintain during the ordinary course of our business operations, and to process such data responsibly in accordance with company policy and any applicable laws.

#### Cybersecurity

Ultragenyx has an information security program with policies and procedures to guide our security and data protection decision-making process. We are regularly updating our systems in an effort to quickly remediate any potential vulnerabilities. We also purchase a fixed amount of cybersecurity and crime insurance coverage to help mitigate some of the risk and potential liability from cybersecurity breaches.

We provide information security training to employees twice per year. The same training is given to other members of our contingent workforce who have some level of access to our internal systems and can be a risk to our information technology infrastructure.

We have consolidated information security and cyber resiliency activities under the leadership of the director of information security and chief information officer (CIO). The CIO regularly reviews the company's cybersecurity program and risks, processes and procedures with the board's Audit Committee.

# 100% of full-time employees

received cybersecurity training in 2021.

#### INTELLECTUAL PROPERTY

We rely on patent protection, trade secrets, know-how and continuing innovation to develop and maintain our competitive position. Our policy is not to tolerate any unlawful use or activity that violates the intellectual property rights of others, as highlighted in the <u>Ultragenyx Code of Conduct</u>. We also expect suppliers with which we conduct business to respect the intellectual property rights of others.

#### RESPONSIBLE PROCUREMENT

# **Objective:** Maintain a high rate of third-party due diligence of our suppliers

To complement and supplement the Code of Conduct, we released the Standard for Suppliers in early 2022. The Standard applies to all suppliers, manufacturers, distributors, vendors, contractors, subcontractors, agents, consultants and providers of goods and services and their employees, or anyone working on behalf of Ultragenyx (collectively referred to as Suppliers), and includes expectations of Suppliers on the topics of integrity and compliance with laws, fair marketing and sales practices, conflicts of interest, labor standards (including forced employment, slavery and human trafficking), human rights, environmental stewardship, global pandemic preparedness and community involvement.

Developing strategic, long-lasting and mutually beneficial relationships with Suppliers is critical to our company's success. We seek to engage with Suppliers that share our values and our commitment to ethics and compliance. Before engaging a new Supplier, we screen for various legal and compliance risks in accordance with company policy. Before payment is issued, we confirm that all third parties are not on watchlists maintained by the U.S. Department of Treasury's Office of Foreign Assets Control (OFAC). We conduct appropriate due diligence on new Suppliers, which includes screening for economic sanctions, anti-bribery and anti-corruption activity, and other review and analysis.

We rely on our internal quality team and external contracted auditors for our Supplier audits.

#### SASB INDEX

The following index lists the accounting metrics from the Sustainability Accounting Standards Board (SASB) Biotechnology and Pharmaceuticals Industry Standard (2018) with associated response, reference or report location.

TOPIC	ACCOUNTING METRIC	SASB CODE	RESPONSE / REFERENCE / REPORT LOCATION
Safety of Clinical Trial Participants	Discussion, by world region, of management process for ensuring quality and patient safety during clinical trials	HC-BP-210a.1	2021 ESG Report, Quality & Patient Safety, Page 15
	Number of FDA Sponsor Inspections related to clinical trial management and pharmacovigilance that resulted in: (1) Voluntary Action Indicated (VAI) and (2) Official Action Indicated (OAI)	HC-BP-210a.2	2021 ESG Report, Quality & Patient Safety, Page 15
	Total amount of monetary losses as a result of legal proceedings associated with clinical trials in developing countries	HC-BP-210a.3	During fiscal year 2021, Ultragenyx was not subject to any material monetary losses resulting from legal proceedings. For more information, see our 2021 Annual Report
Access to Medicines	Description of actions and initiatives to promote access to health care products for priority diseases and in priority countries as defined by the Access to Medicine Index	HC-BP-240a.1	2021 ESG Report, Access & Affordability, Page 19
	List of products on the WHO List of Prequalified Medicinal Products as part of its Prequalification of Medicines Programme (PQP)	HC-BP-240a.2	Ultragenyx does not have any products that qualify for the WHO List of Prequalified Medicinal Products at this time.
Affordability & Pricing	Number of settlements of Abbreviated New Drug Application (ANDA) litigation that involved payments and/or provisions to delay bringing an authorized generic product to market for a defined time period	HC-BP-240b.1	This metric does not currently apply to Ultragenyx's business.
	Percentage change in: (1) average list price and (2) average net price across U.S. product portfolio compared to previous year	HC-BP-240b.2	2021 ESG Report, Access & Affordability, Page 19
	Percentage change in: (1) list price and (2) net price of product with largest increase compared to previous year	HC-BP-240b.3	2021 ESG Report, Access & Affordability, Page 19

TOPIC	ACCOUNTING METRIC	SASB CODE	RESPONSE / REFERENCE / REPORT LOCATION
Drug Safety	List of products listed in the Food and Drug Administration's (FDA) MedWatch Safety Alerts for Human Medical Products database	HC-BP-250a.1	Our three first FDA-approved rare disease treatments for four diseases are not listed in the FDA MedWatch.
	Number of fatalities associated with products as reported in the FDA Adverse Event Reporting System	HC-BP-250a.2	This information for our products can be found in the FDA's Adverse Event Reporting System
	Number of recalls issued, total units recalled	HC-BP-250a.3	2021 ESG Report, Quality & Patient Safety, Page 15
	Total amount of product accepted for takeback, reuse, or disposal	HC-BP-250a.4	Ultragenyx manufactures medicines on a schedule that is designed to avoid their expiration before patient use. In the event that medicines (a) expire before use and are returned, (b) are found to be unsuitable for release or (c) are subject to a recall or withdrawal notice, Ultragenyx does not reintroduce them again for reuse. They get disposed of using regulated and monitored incineration processes.
	Number of FDA enforcement actions taken in response to violations of current Good Manufacturing Practices (cGMP), by type takeback, reuse, or disposal	HC-BP-250a.5	Ultragenyx does not have any products that qualify for the WHO List of Prequalified Medicinal Products at this time.
Counterfeit Drugs	Description of methods and technologies used to maintain traceability of products throughout the supply chain and prevent counterfeiting	HC-BP-240b.1	We employ multiple security features designed to deter or reduce the risk of the use of counterfeited products, such as implementing tamper-evident seals and serializing our products. Furthermore, we have a field action procedure that is initiated if there was a known issue or a known risk that determined a need to communicate to various stakeholders. The procedure includes action items across cross-functional representatives at the company to address an issue, such as suspected counterfeit products or alternate product quality issues.
	Discussion of process for alerting customers and business partners of potential or known risks associated with counterfeit products	HC-BP-240b.3	2021 ESG Report, Quality & Patient Safety, Page 15
	Number of actions that led to raids, seizure, arrests, and/or filing of criminal charges related to counterfeit products	HC-BP-240b.2	None

TOPIC	ACCOUNTING METRIC	SASB CODE	RESPONSE / REFERENCE / REPORT LOCATION
	Total amount of monetary losses as a result of legal proceedings associated with false marketing claims	HC-BP-270a.1	During fiscal year 2021, Ultragenyx was not subject to any material losses resulting from legal proceedings. For more information, see our 2021 Annual Report.
Ethical Marketing	Description of code of ethics governing promotion of off-label use of products	HC-BP-270a.2	Ultragenyx does not promote products for unapproved uses. All promotional communications must meet the requirements of applicable local laws, regulations, industry codes and other applicable guidance documents. Unsolicited requests for information about unapproved uses of Ultragenyx products received by the company while conducting promotional communications must be referred to the medical information team in accordance with applicable Ultragenyx policies and procedures. More information can be found in our Code of Conduct.
Employee Recruitment,	Discussion of talent recruitment and retention efforts for scientists and research and development personnel	HC-BP-330a.1	2021 ESG Report, I&D in Recruitment, Page 31
Development & Retention	(1) Voluntary and (2) involuntary turnover rate for: (a) executives/ senior managers, (b) midlevel managers, (c) professionals, and (d) all others	HC-BP-330a.2	2022 ESG Report, Human Capital Development, Page 26
Supply Chain Management	Percentage of (1) entity's facilities and (2) Tier I suppliers' facilities participating in the Rx-360 International Pharmaceutical Supply Chain Consortium audit program or equivalent third-party audit programs for integrity of supply chain and ingredients	HC-BP-430a.1	Ultragenyx is not reporting against this metric at this time.
Business Ethics	Total amount of monetary losses as a result of legal proceedings associated with corruption and bribery	HC-BP-510a.1	2021 ESG Report, Ethics & Integrity, Page 49
	Description of code of ethics governing interactions with health care professionals	HC-BP-510a.2	2021 ESG Report, Interactions with Patients, Caregivers & Healthcare Professionals, Page 51

The SASB metrics are referenced above for informational purposes only with no claim of fulfillment to any given metric.

#### **REFERENCES**

<u>Ultragenyx Website</u>

Form 10-K

<u>Proxy Statement</u>

<u>Ultragenyx Code of Conduct</u>

Ultragenyx Standard for Suppliers

<u>Ultragenyx Comprehensive Compliance Program</u>

Statement on Transparency in our Supply Chain and Modern Slavery

Corporate Governance Guidelines

**Audit Committee Charter** 

Compensation Committee Charter

Nominating and Corporate Governance Committee Charter

Research and Development Committee Charter

<u>Ultragenyx Careers</u>

Our Clinical Trial Transparency Commitment, including clinical studies and summaries

Our Clinical Trials

Our Pipeline

Our Partners

<u>UltraCare Program</u>

Patient Advocacy at Ultragenyx

Patient Advocacy Group Partners

Resources available to the XLH community in Mexico and Brazil

Resources available to the MPS VII community in English, Spanish, Portuguese, Italian, Polish, Romanian, Hungarian and Croatian

U.S. National Institutes of Health database of privately and publicly funded clinical studies conducted around the world

Lochmüller H, Ramirez AN, Kakkis E., Disease monitoring programs of rare genetic diseases: transparent data sharing between academic and commercial stakeholders. Orphanet J Rare Dis. 2021 Mar 20;16(1):141. doi: 10.1186/s13023-021-01687-7. PMID: 33743771; PMCID: PMC7980582.

# ultragenyx