



Jonathan,  
living with PK deficiency



2024 Agios Pharmaceuticals

# *Environmental, Social and Governance Report*



Agios Pharmaceuticals

## Corporate *Sustainability* Tear Sheet

At Agios, we are committed to building a sustainable business that provides long-term value for all our stakeholders. We support environmental, social and governance (ESG) initiatives that are aligned with our culture and values and that may positively impact the patients we serve, our employees, our communities and our world.

This document contains disclosure of sustainability metrics relevant to Agios' business and strategy. These metrics are aligned with the Sustainability Accounting Standards Board (SASB) standards for the Biotechnology and Pharmaceuticals Industry and the United Nations Sustainable Development Goals (UN SDGs). Unless otherwise noted, it covers ESG disclosures for Agios Pharmaceuticals for the period Jan. 1, 2023 through Dec. 31, 2023.





Agiros Pharmaceuticals

## ↓ A Letter from Our CEO

*On behalf of the entire Agios organization, I am proud to bring you our fifth Environmental, Social and Governance report, highlighting the mission-driven work of our organization to improve the lives of patients living with rare diseases.*

This report comes after an eventful year with great progress across our pipeline as we advance our vision of becoming a leading rare disease company focused on red blood cell health. A few highlights include our Phase 2 RISE UP data readout in sickle cell disease, Phase 2a data readout in lower-risk myelodysplastic syndrome (MDS), a license agreement for a novel siRNA for potential treatment of polycythemia vera (PV), and a Phase 3 ENERGIZE data readout in thalassemia. We also made important strides building our commercial capabilities as we advanced the PYRUKYND® U.S. launch in PK deficiency, laying a foundation for an additional potential launch in thalassemia in 2025 and sickle cell disease in 2026.

The meaning behind these accomplishments is two-fold. First, each step forward brings to life our mission of improving the lives of patients living with rare diseases. And second, it's not just about 'what' we do. 'How' we execute our mission is equally important and a tremendous source of pride for all of us at Agios.

Our ESG approach is wide-ranging, particularly for a company of our size, and this year's report is a shining reflection of our 'how'. We are uniquely fueled by connections we make with our patients, each other, and the communities we work in and operate. I'm particularly proud of the work our organization has done to cultivate an environment that embraces diversity in all its forms – both in the patient communities that we serve and within the physical and digital corridors of Agios. Our efforts across these sectors have been recognized externally, and we are immensely proud of the progress we have made, and our commitment to do more.

**Diversity in our Patient Communities:** robust diversity across our clinical trials remains a priority at Agios. Our relentless focus on inclusivity across all facets of our trial designs is evident in our sickle cell and thalassemia studies, despite the challenges of recruiting and executing studies in rare diseases globally. The diverse patient populations of the diseases we are targeting with our two near-term potential launches should be reflected in the teams that work to bring these drugs to patients. It is the right thing to do – and it makes excellent business sense.

**Diversity at Agios:** Across all facets of the organization, spanning the board, our executive team, and all Agios employees, we believe our representative, experiential, and cognitive differences make us better equipped to achieve our goals, and ultimately, bring successful treatments to patients living with rare diseases. Our ways of working are critical to our success and have been recognized with several awards. We are proud to be leaders in this space, while also acknowledging that we have more work ahead of us to reach our goals. I'm particularly proud of the gender diversity we've grown at Agios. We are uniquely positioned with strong female representation across all layers of the organization – 50% of our board, 63% of our C-suite, 56% of our senior management, and 59% of our employee population identify as female.

We firmly believe that our success is not only tied to milestones or financial performance, but intrinsically linked to doing what is right for our patients, the communities we serve and live in, and society as a whole. We remain steadfast in our commitment to listening, learning, and taking meaningful action to drive positive change within our organization, and beyond.

As I look forward to the coming year, I am grateful to our patients, employees, partners, and all our stakeholders that enable and support us on our journey to becoming a rare disease leader. I look forward to seeing what we can accomplish together. Thank you for your contributions to helping Agios achieve its mission.

## ↓ ESG Program Objectives

Our vision to make the world a better place is foundational to Agios. We are driven to improve the lives of those fighting life-threatening and life-altering rare diseases, including those that have often been overlooked or neglected. We have pioneered two novel therapeutic approaches — IDH inhibition and PK activation — and continue to focus on creating a sustainable business in which innovation on behalf of rare disease patients can thrive.

*Our ESG program is fueled by our connections to:*



### 9 Patients

- 10 Case Study: *Advancing Care for an Underserved Patient Community*
- 12 Access to Medicines and Affordable Pricing
- 15 Safety of Clinical Trial Participants
- 16 Drug Safety
- 18 Case Study: *Elevating Patients' Voices in Research*
- 21 Case Study: *Partnering with the Healthcare Provider Community to Improve Patient Care Globally*

### 23 Employees

- 24 Culture
- 25 Employee Recruitment, Engagement, and Retention
- 27 Diversity and Inclusion
- 32 Health and Safety
- 33 Case Study: *The Way We Work*

### 34 Our Communities & World

- 35 Case Study: *Increasing Diversity in Life Sciences*
- 36 Community Involvement
- 38 Energy and Greenhouse Gas Emissions
- 38 Environmental Stewardship and Corporate Responsibility

### 39 Ethics & Values

- 40 Oversight of Sustainable Practices
- 41 Ethical Business Practices and Marketing
- 42 Data Security and Privacy
- 44 Corporate Governance
- 46 Safe Harbor Statement



*We were founded to unlock a new field of discovery in cellular metabolism.*

Our first application in IDH inhibition resulted in two precision oncology therapies within 10 years.

## We are fueled by *connections.*

Agios is a biopharmaceutical company passionately committed to improving the lives of people living with rare diseases.

The strong bonds we build with patient communities, healthcare professionals, partners and colleagues enrich the impact we have as experts in cellular metabolism. These connections enhance our collaboration, creativity and productivity — driving our ability to develop life-changing treatments.



*We are expanding our impact in rare hematologic diseases.*

Our pioneering research in PK activation has yielded the first approved therapy for a rare, debilitating, lifelong blood disorder. Our robust clinical and preclinical pipeline of rare blood disorder treatments now spans five indications.

### *At a Glance*

**FOUNDED**  
*2008*

**HEADQUARTERS**  
*Cambridge, Mass.*

**1ST APPROVED THERAPIES**  
*2017 & 2018*

**FIRST AND ONLY DISEASE-MODIFYING THERAPY FOR PK DEFICIENCY APPROVED IN THE U.S., EU, AND GREAT BRITAIN**  
*2022*

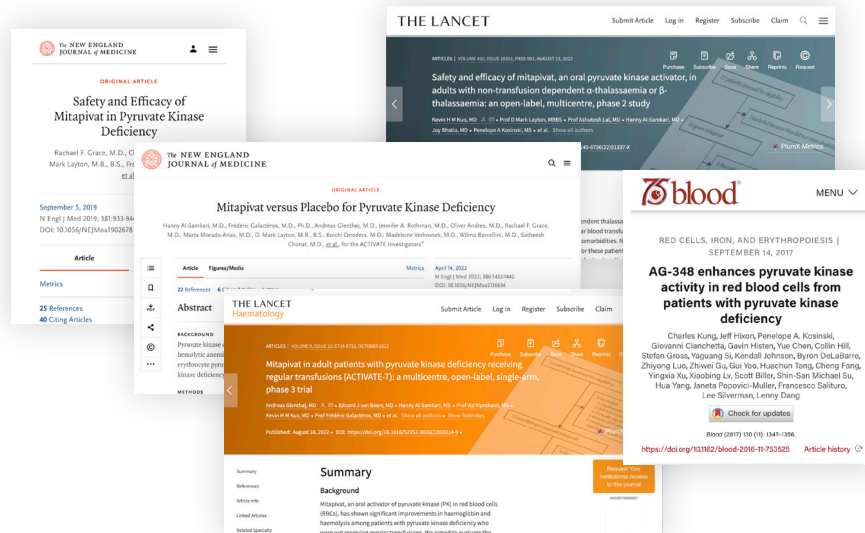
**RARE HEMATOLOGIC DISEASE PROGRAMS**  
*Pyruvate Kinase Deficiency – Adult & Pediatric*  
*Thalassemia – Adult & Pediatric*  
*Sickle Cell Disease – Adult & Pediatric*  
*Lower-Risk Myelodysplastic Syndromes*  
*Polycythemia Vera*

Through our *pioneering leadership* in PK activation, we are making a difference for people with *rare diseases*





*Pivotal Clinical Programs*

-  **ENERGIZE**
-  **ENERGIZE-T**
-  **RISE UP**
-  **ACTIVATE-Kids™**
-  **ACTIVATE-KidsT™**

*Publications*



*Diseases with POC Achieved*

-  **PK DEFICIENCY**
-  **THALASSEMIA**
-  **SICKLE CELL DISEASE**
-  **LOWER-RISK MYELODYSPLASTIC SYNDROMES**

*+ A Lot of Firsts*

*1st* Disease-modifying Therapy for PK Deficiency

*1st* Global PK Deficiency Registry

*1st* Pediatric Study of a PK Activator

*1st* Company to Pursue MDS with a PK Activator

*1st* Clinical Trial Evaluating Disease-modifying Treatment in Alpha-Thalassaemia

*Positive topline results announced in January 2024*

## ↓ Financial Performance

*We invest in ongoing innovation on behalf of people who have few or no treatment options.*

**2023 R&D INVESTMENT**

*\$295.5 million*

**3-YEAR R&D INVESTMENT**

*\$832.4 million*

*Our strong balance sheet enables focused execution on our near- and long-term priorities advancing rare disease therapies.*

In April 2021, Agios divested its oncology business for an upfront payment of \$1.8 billion in order to focus solely on accelerating and expanding its rare disease portfolio.

**CASH & INVESTMENTS POSITION**

*\$806.4 million*

*as of Dec. 31, 2023*

## ↓ *Our Values* Guide Our Actions and Decisions

For us, it's not enough simply to say we have values. We put our values into action by creating and supporting initiatives that positively impact patient communities, the environment, society, our own team and the way we run our business. We believe that by building a sustainable and ethical business foundation, we're able to create deeper and more meaningful connections with all of our stakeholders.

### *Aim High*

We're here to do great things in partnership with patients. We set the bar high for ourselves, and we keep working to raise it. At our core, we're guided by a deep respect for the science and a commitment always to act with the utmost integrity.

### *Come Together*

We foster a caring and open community with our team. We grow supportive relationships with patients and caregivers. We build trusting connections with collaborators. Together, we make a bigger impact than we ever could alone.

### *Embrace Differences*

Because opportunities and insights come from anywhere and anyone, we honor all voices and encourage honest dialogue. We learn equally from success and failure, bringing an open mind and a flexible approach to everything we do.

### *Bring Your Whole Self*

We know we make the biggest impact when each of us can contribute and lead in our own way. So, we honor everything that makes you uniquely "you" — and we never, ever tolerate jerks. At the end of the day, we aim to solve serious problems and have fun doing it.

### *Blaze New Trails*

We ask the tough questions that lead to groundbreaking scientific advances. We nurture a creative mindset and resourceful approach that spark life-changing innovations for patients. No matter where our journey takes us, we keep challenging ourselves and our colleagues to find new and better ways to realize the potential of our science.



# Our Commitment to Patients

## Meet NinaMaria

NinaMaria is a news producer and lives out her dreams despite the challenges of living with thalassemia. She was diagnosed with thalassemia at six months of age. As a child, NinaMaria and her family chose to keep her thalassemia private. Now, she considers when and how to share with others about her condition as a way to raise awareness about thalassemia and advocate for her own health.

“Instead of thalassemia being something that gets in my way or tears me down, I’ve allowed it to be something that has allowed me to learn more about myself and be more confident in myself, to challenge myself, to know myself. I’m a lot stronger and more capable than I ever thought I was.”

Agios is proud to work toward improving the lives of people like NinaMaria.



NinaMaria, living with thalassemia

Check out [this video](#) to hear more of NinaMaria's story



### 2023 Citeline Awards

Winner, Excellence in Rare Disease Drug Development

Finalist, Champion of Diversity and Inclusion in Clinical Trials

Finalist, Excellence in Patient Recruitment & Engagement



### 2023 PharmaVoice Top Industry Leaders

Dr. Sarah Gheuens, Rare Disease Warriors



### 2023 Biotech Week Boston Awards

Finalist, Transformational Therapy



### 2022 Pharma Intelligence SCRIP Awards

Finalist, Best New Drug of the Year



### 2022 Fierce Pharma Marketing Awards

Finalist, Multicultural Campaign  
Finalist, New Brand Launch



### 2018 New England Venture Capital Association NEVY Awards

Patient Impact Award



### 2014 World Economic Forum

Technology Pioneer

3 GOOD HEALTH AND WELL-BEING





## Case Study

## ↓ Advancing Care for an Underserved Patient Community

Sickle cell disease is a debilitating, lifelong blood disorder with tremendous unmet need. Historically, the community has faced a number of systemic barriers to optimal health, such as a lack of research investment in the disease, a lack of access to the best treatments due to finances and a global population with a large percentage of individuals in developing nations, stigmas that frequently result in a lack of listening and empathy from healthcare providers, and issues caused by racism and detrimental social determinants of health. Though the U.S. and EU have seen promising advances in sickle cell treatment in recent years, there are no approved oral treatments that address both sickle cell pain events and chronic anemia.

At Agios, we are committed to innovating on behalf of the global sickle cell disease community and to elevating patients' voices and experiences to help overcome marginalization and improve care for all.

### *Advancing Clinical Research in Sickle Cell Disease Globally*

At the 2023 American Society of Hematology (ASH) annual meeting, Agios presented [positive results](#) from the Phase 2 portion of the pivotal Phase 2/3 RISE UP clinical study in sickle cell disease. In order to ensure RISE UP includes participants who are representative of the diverse sickle cell disease population, Agios has invested significant resources and efforts to work with global sites across North and South America, the Middle East, Europe, and Africa.

In addition, Agios' collaborators at the National Institutes of Health (NIH) and the University of Utrecht both presented long-term data from their respective investigator-sponsored trials (ISTs) at ASH 2023, further reinforcing the potential of Agios' investigational medicine in sickle cell disease.

### *Redefining Best Practices in Clinical Trial Design & Education*

For years, we have partnered closely with sickle cell warriors from around the world to design RISE UP as a clinical trial that is created by sickle cell warriors, for sickle cell warriors. This included asking individuals with sickle cell disease to describe what matters most to them in a trial setting, and involving patients in decision making processes and trial awareness communications. Agios partnered with a sickle cell warrior to present a 2023 ASH Industry Theater event which focused on our patient centric approach to clinical trial design and education in hopes that these learnings would enable others to emulate our approach.

To design the RISE UP study, a steering committee made up of 9 patients and advocates was formed. The committee provided feedback on topics such as meaningful trial parameters, study duration, post-study access to treatment, study endpoints, eligibility criteria, assessments and procedures, operational support needs (e.g., visit frequency and locations), compensation considerations, and pain reporting. Many elements of the study protocol were influenced by this feedback; importantly, when Agios was unable to include all of the patients' feedback due to regulatory guidance, we intentionally shared the rationale with the committee in a timely, transparent manner.



Case Study

## ↓ Advancing Care for an Underserved Patient Community *(continued)*

Agios and sickle cell warriors co-created an awareness campaign for RISE UP to educate the community about this study and about clinical trials in general, to build trust with the community, and to celebrate the strength and resilience of warriors. The campaign was tremendously successful at driving awareness, showing that involving patients can create a uniquely impactful and differentiated awareness approach. Based on patient input, the campaign leveraged communications channels used most frequently by the community, meeting patients where they are, using familiar language, and engaging with their priorities to drive engagement and action.

### *Addressing Medical Racism & Supporting Sickle Cell Centers of Excellence*

For three years, Agios has provided funding to ASH to support its Sickle Cell Centers Workshop, a program to provide useful information and support to institutions that are considering the creation of comprehensive sickle cell disease centers. The program is attended by business officials, healthcare providers, and representatives of the sickle cell community and provides tools and resources to address systemic issues faced by these programs, medical racism, and burnout experienced by patients, caregivers, and healthcare providers. By the end of 2023, 48 institutions had engaged in the program.

### *Honoring, Supporting, and Amplifying Warrior Experiences through Art*

In 2023, Agios sponsored an art exhibit at the Sickle Cell Disease Association of America (SCDAA) Annual National Convention featuring the work of sickle cell warrior and advocate, Hertz Nazaire. A pillar in the sickle cell disease community, Hertz passed away from complications of the disease in 2021. The art exhibit was intended to honor his legacy, support the sickle cell community in their grief, and amplify his experiences – as shown through his poignant art – to help healthcare providers, researchers, and others better understand the challenges of living with sickle cell disease. In 2024, Agios plans to sponsor a traveling exhibit of Hertz’s artwork to share his creations and his journey with even more people, beginning with an event on April 9 in Boston.



Teonna, living with sickle cell disease



## ↓ Agios' Access to Medicines and Affordable Pricing Philosophy

### *At Agios, we forge deep connections*

with patients, providers, policymakers and payers to better meet the needs of people living with rare diseases.

### *Our commitment begins with discovering, developing and delivering*

transformative medicines that address patients' needs. We build on this commitment by supporting patients throughout their journeys. We provide and participate in programs that increase awareness, support accurate and timely diagnosis and enable access to safe and effective treatments.

### *We pledge to set prices for our medicines that balance the benefits*

to patients, caregivers, the healthcare system and society and allow us to help as many people as possible today while investing in innovation to help even more people tomorrow.

## ↓ Guiding Principles Help Inform Our Decisions

These values and beliefs underscore our thinking related to access and pricing



### *Create meaningful outcomes for patients*

We work tirelessly to understand rare diseases, so we can develop medicines that help address the outcomes that are most important to people living with these diseases.



### *Stay connected with communities*

We connect directly with patients, caregivers, advocates, providers, payers and policymakers and are invested in collaborating with them to develop new and better solutions.



### *Emphasize transparency*

We connect communities with the information they need by sharing our data, values, processes and progress as openly as possible.



### *Ensure sustainability to help more patients*

We invest in innovation to help more patient communities, while ensuring we continue to serve the patients of today.



## ↓ Access to Medicines and Affordable Pricing Strategy

*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*

SASB: HC-BP-240A.1

Our goal is for as many eligible patients as possible to have access to our medicines and for out-of-pocket costs for the individual patients to be as reasonable as possible.

### U.S. Access Program for PYRUKYND®

PYRUKYND® (mitapivat) was approved by the U.S. Food and Drug Administration in February 2022. Since approval, *90% of eligible U.S. patients* with commercial health insurance have utilized the PYRUKYND® Copay Program which lowers copay costs to *\$0 per prescription*.

Eligible U.S. patients who are uninsured, underinsured, or rendered uninsured may get help from our *Patient Assistance Program* which offers *free prescriptions*.

We developed myAgiOS® Patient Support Services in close collaboration with the patient, caregiver and provider communities. Through myAgiOS®, we provide:

- A single point of engagement for patients and prescribers for prescription and access support
- Dedicated, clinically trained patient support managers
- Disease education for patients and their caregivers
- Support for patients and caregivers to navigate access to treatment regardless of their insurance carrier or coverage status
- Customized adherence support
- Opportunities to connect with the patient community

More details can be found at [PYRUKYND.myagios.com](https://PYRUKYND.myagios.com)



## ↓ Access to Medicines and Affordable Pricing Strategy *(continued)*

### Our Pledge

We have pledged to price our medicines in a way that reflects the benefits to patients, caregivers, the healthcare system and society and allows us to help as many people as possible today while investing in innovation to help even more people tomorrow.

**As part of our commitment, we are not taking any price increases on PYRUKYND® for five years after FDA approval.**

### Global Access

In connection with our regulatory approvals in the EU and Great Britain, we are currently providing access to PYRUKYND® free of charge for eligible patients in those jurisdictions through a global managed access program. We may provide access to PYRUKYND® for adult patients with PK deficiency in other jurisdictions upon request through the global managed access program, on either a free of charge or for charge basis. Healthcare providers may submit an inquiry on behalf of their patients to Agios for consideration.

[Info for Healthcare Providers Outside the U.S.](#)

### *List of products on the WHO List of Prequalified Medicinal Products as part of its Prequalification of Medicines Programme (PQP)*

SASB: HC-BP-240A.2

Given the focus on rare disease medications, Agios' products do not qualify for the WHO List of Prequalified Medicinal Products.

### *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*

SASB: HC-BP-240B.1

None.



Jim, living with PK deficiency

## ↓ Safety of Clinical Trial Participants

*Discussion, by world region, of management process for ensuring quality and patient safety during clinical trials*

SASB: HC-BP-210A.1

Agios follows all review and approval procedures required by applicable laws and regulations before initiating clinical research. Agios protects patient safety and well-being through appropriate informed consent procedures and Good Clinical Practices. For more information, see [Agios' Code of Business Conduct and Ethics](#).

*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)*

SASB: HC-BP-210A.2

No FDA sponsor inspections in 2023.

*Total amount of monetary losses as a result of legal proceedings associated with clinical trials in developing countries*

SASB: HC-BP-210A.3

No monetary losses resulting from legal proceedings in 2023. For more information, see Agios' [2023 10-K](#).



### Committed to the Humane Treatment of Animals in Research

In early 2023, Agios achieved American Association for Accreditation of Laboratory Animal Care (AAALAC) accreditation for our animal research facility. AAALAC is an internationally recognized standard for application of the highest criteria toward animal welfare, care and usage. This accreditation exemplifies our dedication to excellence in animal care, which results in a better environment for animals and higher quality research for patients.

## *Drug Safety* and Counterfeit Drugs

### *Total amount of product accepted for take-back, reuse, or disposal*

SASB: HC-BP-250A.4

Agios manufactures medicines on a schedule that avoids, to the greatest extent possible, the expiration of product before it is consumed through patient use. In the event that (a) materials do expire before use and are returned or (b) they are found to be unsuitable for release into inventory or (c) they are subject to a recall/withdrawal notice, all materials are destroyed using regulated and monitored incineration processes. In 2023, very low numbers (100) units of PYRUKYND® were returned.

### *Description of methods and technologies used to maintain traceability of products throughout the supply chain and prevent counterfeiting*

SASB: HC-BP-260A.1

Agios has successfully implemented serialization practices into its supply chain such that every unit has a unique identifier. Agios has successfully implemented serialization practices into its supply chain such that every unit has a unique identifier. As such, if any transaction involving falsified product were to take place, the supply chain can be immediately halted.

### *Discussion of process for alerting customers and business partners of potential or known risks associated with counterfeit products*

SASB: HC-BP-260A.2

Agios has internal processes in place to ensure that customers and business partners are notified if counterfeit or unsafe products are detected in the supply chain. As of December 31, 2023, no alerts have been received.

### *Number of actions that led to raids, seizure, arrests, and/or filing of criminal charges related to counterfeit products*

SASB: HC-BP-260A.3

None.

### *List of products listed in the Food and Drug Administration (FDA) MedWatch Safety Alerts for Human Medical Products database*

SASB: HC-BP-250A.1

PYRUKYND® (mitapivat) is included in the FDA MedWatch database.



## ↓ *Drug Safety* and Counterfeit Drugs

*(continued)*

*Number of fatalities associated with products as reported in the FDA Adverse Event Reporting System*

SASB: HC-BP-250A.2

As of December 31, 2023, no fatalities have been assessed as related to Agios products (mitapivat & AG-946) as reported in the FDA Adverse Event Reporting System, which can be found [here](#).

*Number of recalls issued, total units recalled*

SASB: HC-BP-250A.3

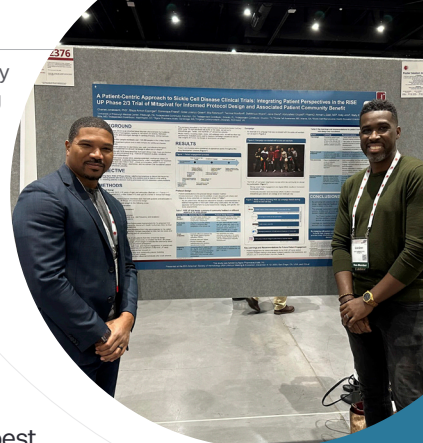
Agios has not been subject to any FDA recalls.

*Number of FDA enforcement actions taken in response to violations of current Good Manufacturing Practices (cGMP), by type*

SASB: HC-BP-250A.5

Agios has not had any GMP violations or FDA enforcement actions.





## Case Study



## *Elevating Patients' Voices* in Research

Agios is committed to partnering with our key stakeholders at every step of the research and development process. In 2023, Agios team members, patients, caregivers, and physicians presented insights about how industry, advocacy, and clinicians can best collaborate to drive truly patient-centered research at major medical and advocacy meetings. These insights were based on several collaborative initiatives that these individuals participated in, including:

**Agios Vision Project:** The goal of this work was to set a vision for “gold standard” patient engagement and experience leveraging insights from internal and external stakeholder interviews and an energizing in-person workshop with patients, advocates, caregivers, and physicians that span Agios’ three initial hemolytic anemias of focus: PK deficiency, thalassemia, and sickle cell disease.

**Red Cell Revolution:** Born out of the Vision Project, the [Red Cell Revolution](#) is a multi-stakeholder advisory council that brings together patients, caregivers and physicians from these communities, which share commonalities in underlying disease pathology, difficulties in transitioning from pediatric to adult care, and immense quality of life concerns, to generate published evidence and meaningful solutions that are relevant across disease areas. The group collectively uses their voices to raise awareness about the needs and experiences of people touched by these diseases.

**RISE UP Patient Steering Committee:** Agios’ RISE UP clinical study utilized an innovative, patient-led approach to support informed protocol design, raise clinical trial awareness, and improve enrollment into the study.

See [case study](#) on advancing care for an underserved patient population.

### **PK Deficiency Advocacy Advisory Council (AAC):**

The PK deficiency AAC is a global, multi-disciplinary group of patients, caregivers, patient advocates, and healthcare providers (HCPs). The AAC is designed to help set the direction for Agios’ PK deficiency patient advocacy efforts and ensure value is being delivered through Agios’ community projects and programs.

### **Thalassemia Advocacy Advisory Council (AAC):**

The thalassemia AAC is a global, multi-disciplinary group of patients, caregivers, patient advocates, and healthcare providers (HCPs). The AAC includes individuals from different countries, backgrounds, and perspectives to discuss key priorities in thalassemia care, define unmet needs, and develop solutions that improve patients’ lives. Insights gathered at AAC meetings are intended to ensure that Agios’ activities in thalassemia deliver value for those affected by the disease. In addition, AAC group members have opportunities to implement projects that will help their local and global patient communities.

Case Study



## Elevating Patients' Voices in Research

### 2023 Presentations

The following were presented by patients, caregivers, advocates, physicians, and Agios representatives in 2023:

#### *Sickle Cell Disease Association of America (SCDAA) Annual National Convention*

- **Red Cell Revolution:** “Finding common ground: a pan-disease advisory council to uncover shared unmet needs in hemolytic anemias” – oral presentation  
– Presenter(s): *Rae Blaylark, sickle cell caregiver & advocate*
- **Patient Advocacy RISE UP:** “RISE UP campaign: raising the bar on patient involvement in clinical development” – oral presentation  
– Presenter(s): *Golie Lorenzo-Green, sickle cell warrior & advocate*  
– Awards/recognitions: *Best Oral Presentation 2023*

#### *National Organization for Rare Disorders (NORD) Breakthrough Summit*

- **Vision Project:** “Setting Industry Standards for Patient Engagement, Partnership and Care: The Patient Vision Project”  
– poster & oral presentation  
– Presenter(s): *Rucha Shah, thalassemia patient & advocate*  
– Awards/recognitions: *Top Poster & Lightning Presentation (1 of 7 selected)*

Sickle Cell Disease Association of America (SCDAA) Oral Presentation of the Year

Dominique Friend, Golie Lorenzo-Green, Teonna Woolford, DeMitrious Wyant



- **PK Deficiency AAC:** “Understanding the psychosocial impacts of rare disease: patient-led research in pyruvate kinase deficiency” – poster  
– Presenter(s): *Tamara Schryver & Laura Miller-D’Angelo, PK deficiency patients & advocates*

#### *Annual Academy of Sickle Cell and Thalassaemia Conference (ASCAT)*

- **Red Cell Revolution:** “Finding common ground: a pan-disease advisory council to uncover shared unmet needs in hemolytic anemias” – oral presentation  
– Presenter(s): *Cassandra Trimnell, sickle cell warrior & advocate; Dr. Biree Andemariam, physician*
- **Patient Advocacy RISE UP:** “RISE UP Campaign: raising the bar on patient involvement in clinical development” – oral presentation  
– Presenter(s): *Holly John, Agios*  
– Awards/recognitions: *Selected as 1 of 3 plenary presentations*

#### *Thalassemia International Federation (TIF) Conference on Thalassemia & Haemoglobinopathies*

- **Thalassemia AAC:** “Investigating Health Literacy in Thalassemia: The Importance of Obtaining Multi-Stakeholder Perspectives in Improving Health Outcomes Among Patients” – poster  
– Presenter(s): *Lily Cannon, thalassemia advocate*

Case Study



## *Elevating Patients' Voices* in Research

### *American Society of Hematology (ASH) Annual Meeting*

- **PK Deficiency AAC:** “Understanding the Physical and Psychosocial Impacts of Pyruvate Kinase Deficiency: Patient-Led Development of the Pyruvate Kinase Deficiency Life Phase Model” – poster  
– *Presenter(s): Dr. Rachael Grace, physician; Tamara Schryver, PK deficiency patient & advocate*
- **Red Cell Revolution:** “Cross-community collaboration and data collection to optimize patient care in hemolytic anemias” – poster  
– *Presenter(s): Dr. Biree Andemariam, physician; Rae Blaylark, sickle cell caregiver & advocate*  
– *Awards/recognitions: Selected for Best of ASH interview series*
- **Patient Advocacy RISE UP:** “A patient-centric approach to sickle cell disease clinical trials: integrating patient perspectives in the RISE UP Phase 2/3 trial of mitapivat for informed protocol design and associated patient community benefit” – poster  
– *Presenter(s): Dr. Charles Jonassaint, psychologist; Golie Lorenzo-Green, sickle cell warrior & advocate*

### What's Next

The Red Cell Revolution, in partnership with Agios, has kicked off a robust patient- and physician-led research project focused on patients' experience with physical and emotional fatigue across PK deficiency, thalassemia, and sickle cell disease. Fatigue was identified by the advisory group as a key issue experienced by all three disease areas that is not well understood or characterized. Further publications and presentations are expected to arise out of this research.



*Congratulations!*

Hadiyah Audil, M.D.  
Mayo Clinic

Recipient, Agios Hemolytic Anemias  
Clinical Fellowship Competitive Grant

“Investigating Non-Immune  
Hemolytic Anemia in  
Myelodysplastic Syndrome”

Case Study

## ↓ Partnering with the Healthcare Provider Community to Improve Patient Care Globally

Agios is committed to partnering with third-party organizations, institutions, and clinicians, who serve at the front lines of patient care and the forefront of clinical research. Supporting these dedicated, hardworking, and caring individuals with independent education grants and in advancing their research efforts is an important approach to improving care for patients with rare blood disorders around the world.

### *Unrestricted medical education grants*

Agios provides unrestricted grants for independent medical education to support leading organizations' efforts to advance knowledge in medicine and healthcare by improving awareness and understanding of rare blood disorders in the medical community. In 2023, Agios provided more than \$600,000 in unrestricted grants. The organizations used this funding to develop resources such as:

- Guidelines for the Management of Non-transfusion-dependent Thalassemia, 3rd Edition [Thalassemia International Federation (TIF)]
- Diversity, Equity, and Inclusion in Sickle Cell Disease: Creating a Space for All Patients [2023 American Society of Hematology (ASH) Independent Satellite Symposium]
- Patient, Provider, and Caregiver Connection: Developing Strategies to Improve Patient Access to Care for Thalassemia – Understanding Patient Challenges and the Role of Innovative Treatment [Physicians' Education Resource]
- Cases in Alpha-Thalassemia: What Is the Role of Primary Care? [Medscape Continuing Medical Education (CME)]
- Considering Best Practices in Sickle Cell Disease Management [Med Learning Group, LLC]

### *Competitive research grant for healthcare professionals dedicated to scientific advancements in hemolytic anemias*

Agios is dedicated to the advancement of current and future generations of skilled healthcare professionals who are driving innovation, better patient care, and improved outcomes in classical hematology.

In 2023, Agios provided the second Agios Hemolytic Anemias Clinical Fellowship Competitive Grant, which is intended to increase the number of skilled clinicians committed to providing comprehensive care for individuals living with hereditary hemolytic anemias, with a focus on hemoglobinopathies such as thalassemia (alpha and beta) and sickle cell disease. Through this grant, Agios provides award funding of up to \$75,000 to a physician conducting clinical or scientific research in hereditary hemolytic anemias to cover costs related to fellowship training and fellowship research. It is the aim of the fellowship grant that graduates will become expert clinicians and role models in the field of classical hematology. Ideal candidates will strive to be leaders who exhibit the potential to become outstanding mentors in their own right – able to provide training and support to other future clinicians in hereditary hemolytic anemia care.



John, living with PK deficiency

Case Study

## ↓ Partnering with the Healthcare Provider Community to Improve Patient Care Globally *(continued)*

### *Investigator-sponsored trials (ISTs)*

Agios partners with leading researchers and institutions around the world to further knowledge and understanding of rare blood disorders globally. Agios supports ISTs and other research activities that are designed to provide meaningful scientific insights, including:

- The International Hemoglobinopathy Research Network (INHERENT): The ultimate goal of this initiative is to undertake a large-scale multi-ethnic genome-wide association study (GWAS) to inform patient stratification and personalized treatment. Agios is supporting a pilot study of 400 patients that aims to determine the operating feasibility of the network procedures and protocols as a precursor to a larger study targeting recruitment of at least 30,000 hemoglobinopathy patients. Established in 2020, the INHERENT network comprises nine existing consortia and now spans 45 countries. Learn more on the INHERENT website, ClinicalTrials.gov, and the autumn 2023 issue of the Agios-supported *Thalassemia News*.
- Registry for Thalassemia and Hemoglobinopathies in Spain: Leading researchers in Spain are developing a national registry to collect demographic, clinical, diagnostic, and genetic classification data, as well as treatment information, for patients with alpha- and beta-thalassemia as well as related hemoglobinopathies to better characterize the patient journey in Spain.
- Panorama of Thalassemia and Sickle Cell Anemia in Brazil: ABRASTA – a leading non-governmental organization also known as the Brazilian Thalassemia Association – aims to gather and analyze Brazil Ministry of Health data on patients with thalassemia and sickle cell disease to better characterize the state of these diseases in Brazil.



Natalie,  
living with thalassemia



Dominique, living with  
sickle cell disease

# Our Commitment *to Employees*

Agios is a supportive, fun and flexible environment full of people empowered to bring their whole selves to work and motivated to make a positive impact for those living with rare diseases. We cultivate this environment in part by hiring and retaining people who care deeply about our mission, about each other, and about the people who count on us.



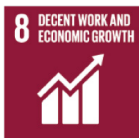
**2024 USA Today**  
*Top Work Place*



**2023 Boston Globe**  
*Top Work Place MA*



**2023 Biospace**  
*Best Places To Work*



## ↓ Our Culture

### *Building a connected and caring environment*

At Agios, our deep sense of caring is what drives every person on our team and enables us to do meaningful work on behalf of people with rare diseases. It is central to our people development strategy and our approach to human resources. It is the reason we regularly ask our people about their experiences at Agios and what we can do to improve our programs and enhance our environment. We eagerly listen to our team's feedback, analyze what we hear and use the findings to make informed decisions that help us continue to be a great place to work.

*Every effort we employ to build and sustain this type of environment is guided by our three pillars.*

### *Flexibility*

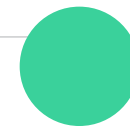
Employees with access to flexibility are happier, more engaged and more productive. Flexibility is about individual needs — it's not one size fits all. We encourage a culture that promotes different perspectives, work styles, health & wellness, care of families and productivity.

### *Psychological Safety*

Based on research initially conducted by Google, we know that high performing teams exhibit psychological safety — the belief that risk-taking and failure won't be punished. We encourage everyone on the team to speak up if something goes wrong or if they disagree or see a different way to approach our work. This leads to more creativity and candor and better results.

### *Deliberate Development*

We emphasize providing ongoing opportunities for employees to grow professionally, whether through bringing in external speakers, offering preceptorships in different departments or providing stretch assignments.



## ↓ Employee *Recruitment, Engagement and Retention*

### *Discussion of talent recruitment and retention efforts for scientists and research and development personnel*

SASB: HC-BP-330A.1

We focus on retaining and hiring people who care about our important work, and who share in our passion and purpose to fuel meaningful connections across our organization and with the communities we serve.

We maintain a focus on the growth and fulfillment of all employees by investing in both shared and individualized offerings to promote an engaging and deliberately developmental culture.

Some of the talent development and retention programs Agios offers include:

- Tuition reimbursement
- Mentorship, internship, and fellowship programs
- Leadership development for managers
- Quarterly check-ins between managers and employees anchored to key themes to support our values and cultural pillars
- ‘Stay interviews’ and motivators checklist to ensure we are staying close to what matters most to our employees
- DevelOPPortunities program: Recognizing career growth occurs in a variety of ways, these temporary, part time assignments provide employees with an opportunity to build new, differentiated skill sets while maintaining current role
- Cross-functional internal moves are encouraged when aligned with employee career interests, and internal transfers are part of our culture
- We are committed to professional growth; our 2023 internal promotion rate was 16.2% - indicative of our commitment to coaching and feedback across our high-performing and deliberately developmental organization

- Half of our current C-suite roles have been filled through internal promotions of highly effective leaders
- Equity for employees with flexibility to select the percentage of restricted stock units (RSUs) vs. stock options

Identifying and recruiting top talent is critical to our growing organization. To do so, we leverage internal networks and a variety of external resources such as professional organizations, academic institutions, career sites, job fairs, and industry conferences. We take a creative approach to identify and assess a diverse pool of candidates for all our openings including:

- Facilitating interview training for all interviewers, including a section on unconscious bias and valuing differences to reinforce our commitment to hiring a diverse team
- Providing hiring managers with 360° assessments of candidates using Agios competencies
- Leveraging additional interviewers outside of candidates’ functional area to assess value fit and culture add
- Adhering to our equal opportunity employment policy
- In 2023, we began using gender decoding tools on all job postings to identify and minimize language that may discourage all qualified candidates from applying to open positions
- Holding proactive, open, and honest conversations with hiring managers and leaders about the existing make-up of teams to identify gaps in representative, experiential, and/or cognitive diversity and ensure the candidate pool reflects individuals who may fill those gaps
- Continuously reviewing and improving our interviewing practices



## ↓ Employee *Recruitment, Engagement and Retention* (continued)

### *Employee Engagement*

We conduct a full organizational health survey every 2–3 years and supplement that with more frequent, targeted pulse surveys to measure key performance indicators of employee engagement and satisfaction. In 2023, 86% of employees participated in our full organizational health survey sharing many points of pride.

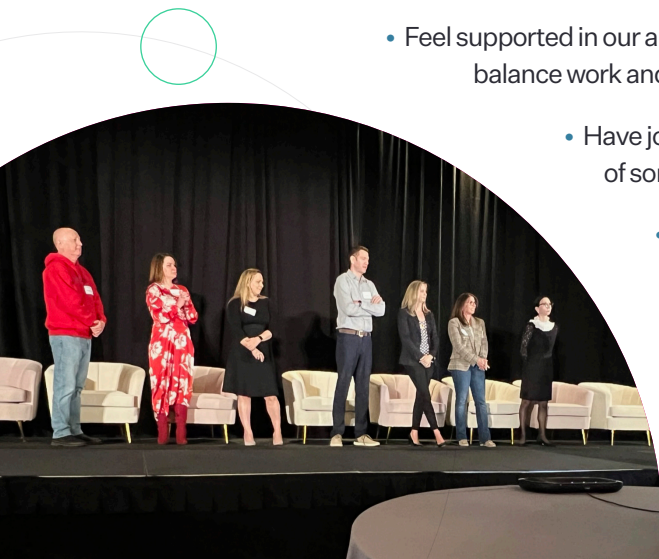
Greater than 90% of all of survey respondents shared in agreement that at Agios, we:

- Are proud to work for Agios
- Put the right amount of attention on understanding and helping patients in everything we do
- Can speak up when we have an idea
- Know how our individual work contributes to the goals of Agios
- Have managers who care about our concerns
- Feel supported in our ability to exercise flexibility to help balance work and personal priorities
- Have jobs that make us feel like we are part of something meaningful
- Have confidence in our leadership team members

At Agios, when we ask for feedback not only do we listen – we act. We take pride in turning organizational health data into meaningful action plans and experiments designed to identify and to improve company culture and the employee experience. Progress against action plans is shared with the entire company regularly. Examples of past experiments include, but are not limited to:

- In response to employee feedback from 2020 surveys, Agios utilized input to inform the design of our post-COVID model of distributed work.
- Additionally, we’ve utilized our DE&I survey to continue to form our approach to creating an inclusive workplace, with improvements to our talent acquisition strategy, an expanded speaker series, and access to learning and volunteer opportunities.
- Driving connections through online *CoffeePals* meetings of employees across different functional areas

Other Agios benefits that have evolved as a result of employee feedback include: discretionary time off policy, two company shutdowns, expanded parental and family leave, a lifestyle spending account, and an inclusive family forming benefit. Additionally, we strive to provide adaptive and robust total rewards to remain competitive and ensure we are meeting the needs of our workforce. For example, in 2023, Agios provided an "inflation support account" to help Agios employees and their families navigate the rising costs of essentials such as utility bills, groceries, gas, and more during an unusually high inflationary period. In 2024, all employees were granted an increase in lifestyle spending funding as we aimed to further encourage employees to invest in their own well-being by disconnecting and recharging outside of work.

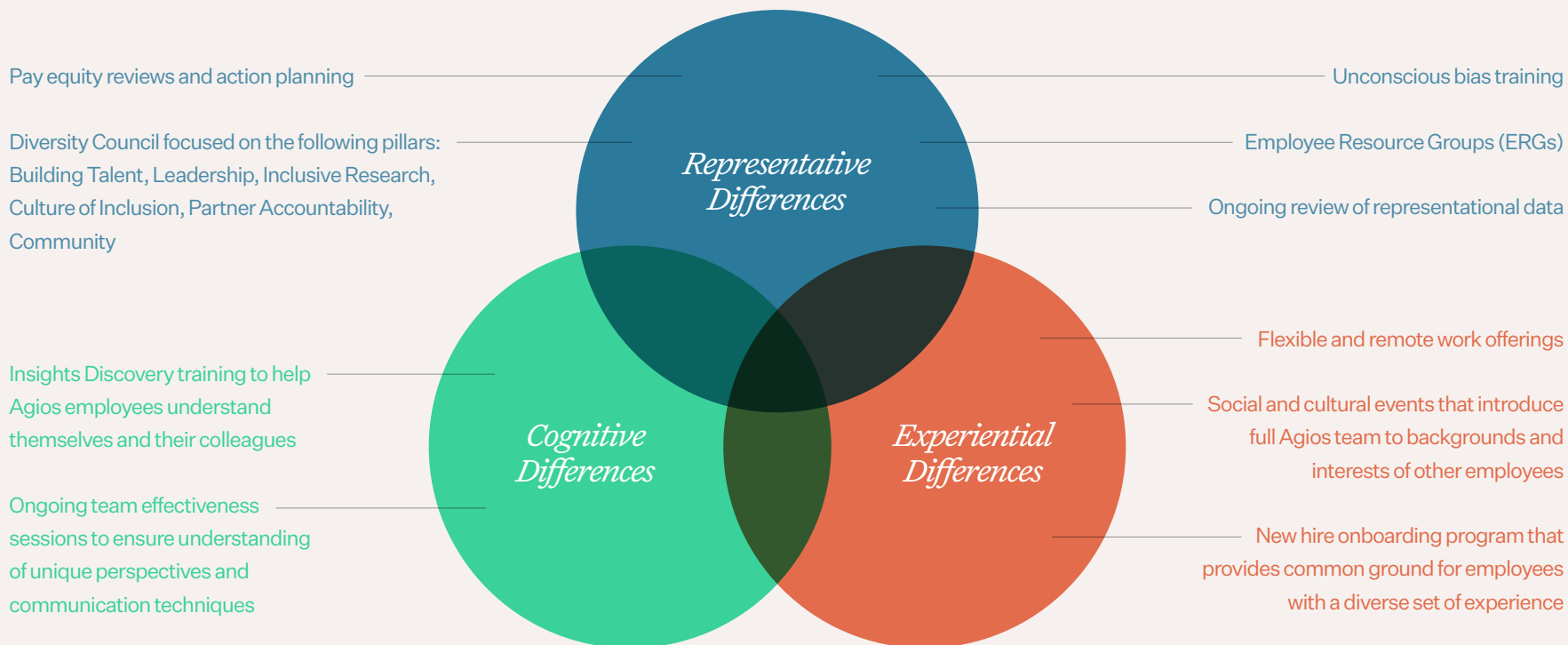


## ↓ Diversity and *Inclusion*

### Diversity Program

Our approach to diversity, equity and inclusion (DE&I) is guided by our Valuing Differences framework. This framework helps drive our culture and innovative spirit. It acknowledges the types of differences that exist among people, and it provides Agios with a guide for ensuring these differences are reflected, embraced and honored in the people we hire and work we do. The three types of differences that shape our team are representative differences (demographic diversity, such as gender, race, ethnicity, sexual orientation), experiential differences (identities based on life experiences that may change over time) and cognitive differences (unique ways of understanding and interpreting the world).

Actions we take to encourage diversity across each of these facets include:



↓ Diversity and *Inclusion* (continued)

A commitment to diversity, equity, and inclusion (DE&I) is an ongoing journey; we recognize there is always more to do. We also believe that *measuring progress is critical to ensuring that our DE&I efforts are having a real impact* on our teams and communities. We are pleased to share that responses to the following DE&I questions on our 2023 companywide survey were overwhelmingly positive.

### Companywide Survey

DE&I Statements

<i>Statement</i>	<i>% Favorable Score</i>
	2023
<b>Agios supports diversity, equity, and inclusion initiatives internally.</b>	<b>91%</b>
<b>I can bring my whole self to work.</b>	<b>90%</b>
<b>My team respects differences across all team members.</b>	<b>90%</b>
<b>Agios does a good job respecting demographic differences (ex: gender, race, ethnicity, sexual orientation) that exist within the organization.</b>	<b>90%</b>
<b>We hire people with demographic differences.</b>	<b>90%</b>

## ↓ Diversity Initiatives

### *Diversity Council*

As an extension of our Valuing Differences framework, the Agios Diversity Council is an employee-led group which works in partnership with Agios leadership, human resources, and Employee Resource Groups to shape, drive, and lead the actions that help Agios achieve our diversity, equity, and inclusion (DE&I) goals. We believe that valuing our differences brings richness to our work environment, creates competitive advantages for our business, and better connects us to the needs of one another and the patients we serve.

The Diversity Council has six working groups, or pillars, that drive progress and alignment around our major areas of focus:

#### **Build Talent Pipeline: Hiring & Retention**

Support a recruitment and interview process that attracts a more diverse pool and ensures they're treated equitably

#### **Leadership**

Hold people leaders accountable for diversity objectives

#### **Inclusive Research: Health Disparities**

Understand what it will take to recruit more representative populations in clinical research

#### **Culture of Inclusion**

Create an environment where all employees can bring their authentic selves to work every day and differences are valued

#### **Partner Accountability**

Prioritize vendors/partners who demonstrate valuing diversity & inclusion

#### **Community**

Demonstrate our support for underserved communities with our time and resources

In 2023, the Agios DE&I Council doubled in size to more than 30 members strong, and there is palpable enthusiasm, support, and passion across the company for the Council's work. In addition, in 2023, Agios doubled the number of employee resource groups (ERGs).

### *Advancing DE&I in Our Communities*

The Diversity Council is not only dedicated to advancing DE&I within our company and team, but also to lending our voice to encourage increased DE&I externally among our partners and communities.

**Inclusive Research:** Agios' Diversity Council, along with relevant cross-functional Agios teams, are working to address health disparities and identify opportunities through collaborations with patient advocacy groups or other organizations.

**Supplier Diversity:** Agios is focused on growing our business with diverse suppliers and ensuring our largest supplier partners have an equally strong commitment to DE&I initiatives. In 2022, we began using public data sources to identify diverse suppliers to invite to new business opportunity requests for proposal. In 2023, we continued to focus on identifying new diverse suppliers with whom to initiate business in order to grow our diverse supplier percentage above our 2021 benchmarks. In 2024, we plan to send a short survey to any supplier starting new work with Agios to indicate DE&I focus. Additionally, we will initiate disease sensitivity training with select vendors.

**Community Relations:** See our [case study](#) on how we're working to increase diversity in the life sciences industry.

↓ *Diversity Initiatives (continued)*

*Employee Resource Groups (ERGs)*

*Agios Association of Black Professionals (AAOBP)*

The AAOBP is dedicated to articulating, supporting and advancing the needs and goals of Agios Black professionals.

*LatinX ERG*

The LatinX ERG strives to develop a network of employees, increasing engagement, relationships, and visibility of its members within and outside of Agios. The ERG is focused on enhancing understanding and knowledge of LatinX cultures.

*Agios Pride ERG*

The Agios Pride ERG seeks to create a supportive and affirming environment for lesbian, gay, bisexual, transgender, queer, questioning and asexual (LGBTQIA) employees and allies.

*Agios Women Leadership & Inclusion ERG*

The ERG is dedicated to empowering, developing, and elevating women in STEM and women of color at Agios. The ERG aims to foster an inclusive community to discuss and create awareness around unique barriers/biases women in STEM and women of color face in the workplace, provide thoughtful resources and partnerships that can advance creativity and leadership opportunities for women.

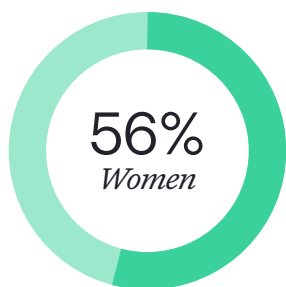




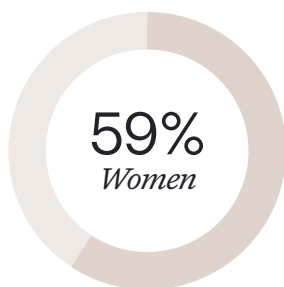
## ↓ Diversity Snapshot

### Gender Diversity

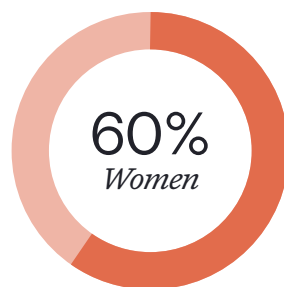
Executive/Senior Manager



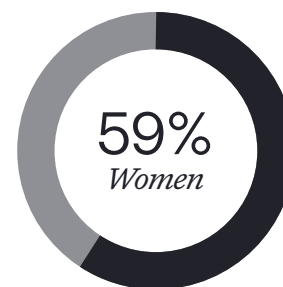
Mid-Level Manager



Professional

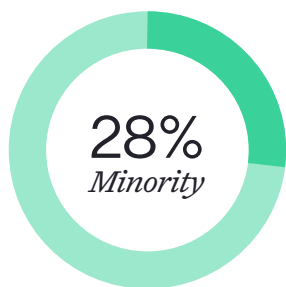


Total

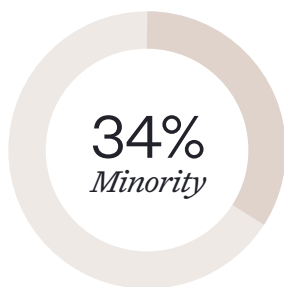


### Racial and Ethnic Diversity

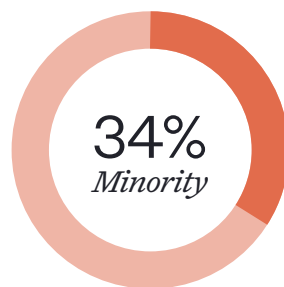
Executive/Senior Manager



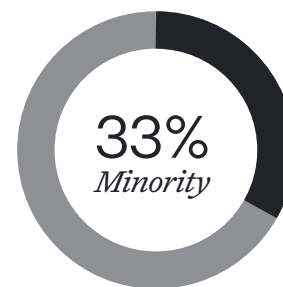
Mid-Level Manager



Professional



Total



Asian	19%
Black or African American	1%
Hispanic or Latino	6%
Other Minority*	2%

Asian	23%
Black or African American	5%
Hispanic or Latino	3%
Other Minority*	3%

Asian	14%
Black or African American	9%
Hispanic or Latino	6%
Other Minority*	6%

Asian	21%
Black or African American	5%
Hispanic or Latino	4%
Other Minority*	3%

\* Includes Native Hawaiian or other Pacific Islander as well as employees with two or more races | Data as of Dec. 31, 2023

## ↓ *Health and Safety*

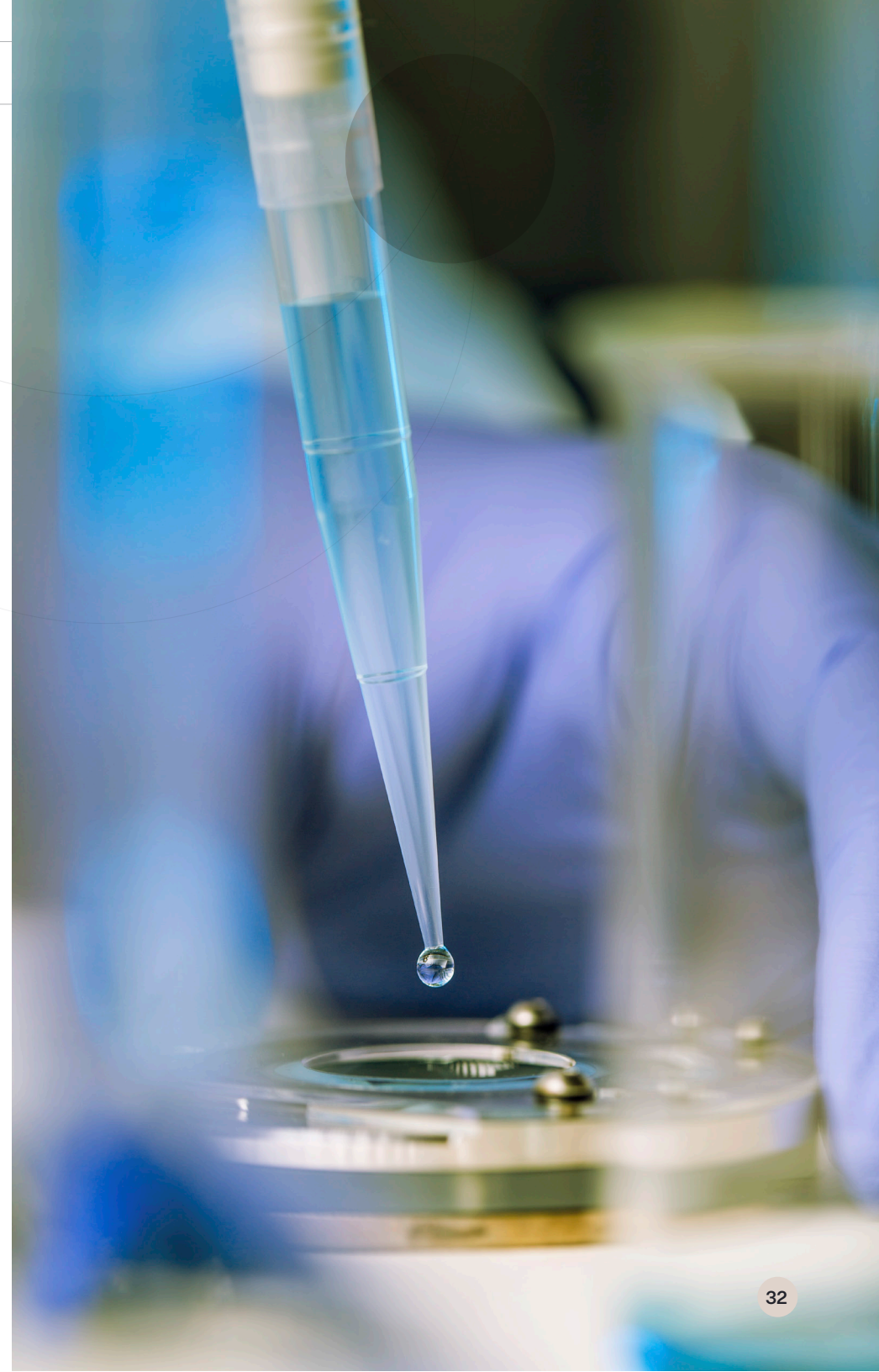
### *OSHA Health and Safety Records and Certifications*

Agios rates of injuries, illnesses and DART (days away, restricted or transferred) are below industry averages. Zero OSHA recordable accidents occurred at Agios in 2023. Health and safety certifications include: CSP and ASP (by BCSP), OSHA 40-hour HAZWOPER, and RCRA/DOT. Agios maintains a comprehensive Emergency Action Plan and a First Aid Response Team of employees certified in First Aid/CPR/AED.

### *Health and Safety Program*

Agios is committed to ensuring a safe and healthy work environment, free from threats to the health, safety, and well-being of our employees and visitors. Agios offers a robust health and safety training program for employees in all roles. Training for all employees includes: EHS overview during new hire orientation, hazard communication, ergonomic principles, evacuation procedures and emergency medical notification, and job-specific training. All employees working in or entering a laboratory setting receive additional Lab Safety Training, which covers lab safety, chemical safety, biosafety, bloodborne pathogens, respiratory protection, personal protective equipment (PPE) and pathogen-specific training.

Auditing processes include external environmental audits conducted every three years, internal regulatory compliance assessments conducted throughout the year, OSHA safety and biosafety program audits conducted externally every three years and annual program evaluation conducted internally.



## Case Study



## The Way We Work

*Agios' approach to workplace flexibility* offers all location-agnostic team members (i.e., those who are not based in a lab or in the field interacting with healthcare providers) the option to choose where they work — fully remote, fully in the office, or hybrid.

### How It Started

Even before the COVID-19 pandemic, Agios was dedicated to *embracing flexibility and differences*. These efforts not only included equipping our team with remote working technology, which most companies have, but importantly we fostered a culture that promotes different perspectives, work styles, health and wellness, care of families, and productivity. With a *culture that supports individual employee needs* already in place, we were able to respond nimbly to the unprecedented challenges of the COVID-19 pandemic and continue serving the patients who are counting on us.

We then took our learnings and experiences from the pandemic to initiate a pilot program in September 2021, allowing our team members to have complete flexibility in where and when they do their work. Through COVID, we saw that our team maintained their productivity and dedication to our mission — and we saw no reason to reduce flexibility as the world slowly began returning to a “new normal.”

### How It's Going

At Agios, every significant decision that affects our team is data-driven and made with *employee input and feedback*. We conducted surveys to help design our workplace flexibility program and to gauge its effectiveness; the feedback to date has been overwhelmingly positive.

In addition, the opportunity to work remotely has opened doors for us to hire a more diverse team including individuals from different locations and backgrounds and with a variety of responsibilities in their personal lives. Our approach and commitment to flexibility has supported an increase in representative diversity of new hires in 2023 (increase of ~7 percentage points from 2022). *In 2023, approximately 84% of our new hires chose to work remotely.*

We strive to support our team's work/life balance by offering at least one holiday or synchronous day off per month, including week-long companywide summer and winter shutdowns. We also encourage high-quality in-person touchpoints such as our companywide Agios Connect events and one optional on-site “anchor day” each week.



*I saw my dream job in patient advocacy posted as a remote role by Agios Pharmaceuticals on LinkedIn. Given my commitments as a mom and caregiver, I was not able to move to Boston. However, the great workplace transformation gave me an opportunity to work at Agios despite living in Chicago.*

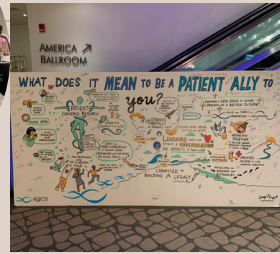
*Previously, I commuted 52 miles one way in Chicago traffic which regularly took over two hours from my day — 10+ hours per week, 50+ hours a month, 600+ hours per year! If it snowed or rained, I experienced an even longer commute time! Working remotely at Agios has taken a lot of unproductive time out of my work and home life.*

*What does a better work/life balance look like for me? It allows me to work out in the morning and then check on my dad who has Alzheimer's while still making it on time to the morning WebEx meeting. It allows me the flexibility to attend my daughter's senior year class presentation within minutes after I've gotten off a call with patient advocates. I show up as my authentic self and am completely present for both meetings.*

*At Agios, I have been able to quickly build bonds with colleagues and multiple stakeholders, all from my home office. It also allows me to focus on what really matters — at work AND home.*

Janie Young Davis,  
Director, Patient Advocacy





# Our Commitment to Our Communities and World

Agios is committed to supporting and connecting with our communities and to doing our part to support a cleaner, healthier planet.

*We act on this commitment by:*

*Being a Good Neighbor*  
Helping to meet the fundamental needs of those around us

*Promoting Diversity, Equity and Inclusion*  
Increasing diversity in STEM education and careers and supporting health equity

*Supporting Holistic Needs of Patients*  
Complementing our pursuit of innovative medicines by meeting non-therapeutic needs for patient communities



**2022 Pharma Intelligence SCRIP Awards**  
*Finalist, Community Partnership of the Year*



**2020 Barron's**  
*Top 100 Sustainable Companies*







## Case Study



## Increasing Diversity in Life Sciences

We believe every voice has value. When people from a variety of backgrounds work together and contribute freely, we can be more innovative and bring about better outcomes for people living with rare diseases. That's why a pillar of our Community Relations program is *increasing diversity in our industry* and *improving health equity* by *improving representative diversity* in healthcare.

### *Showing Students There's a Place for All in STEM*

We love connecting with students from all backgrounds and helping to spark their interest in STEM. We want every student to know that there's a place for them in these fields. In 2023, we volunteered in our community with outstanding organizations that share this mission, including:

Created more than 1000 hands-on STEM (science, technology, engineering, and math) kits for students at under-resourced schools during our companywide Agios Connect event, via a partnership with [Generus](#)

Participated in Life Science Cares' [One-to-One](#) networking program, which provides local under-resourced college students with access to industry professionals for one-on-one conversations around networking and career exploration.

### *Providing Early Career Opportunities*

The earliest career experiences can sometimes be the most difficult to find for those looking to break into the biopharma industry — particularly those who are under-resourced or underrepresented. At Agios, we strive to open the door to our industry through participating in the following programs:

- [MassBioEd Life Sciences Apprenticeship Program:](#) Apprenticeship programs provide accelerated job training, foundational knowledge and hands-on skills to launch a career in a critical, state-of-the-art role in the life sciences industry.
- [Project OnRamp Internships:](#) These summer internships offer rewarding life sciences industry experiences to talented undergraduates from low-income backgrounds. In 2023, we provided internships to two Project Onramp students and we plan to double that number in 2024.

### *Supporting Healthcare Providers Treating Underserved Conditions*

Agios serves people living with conditions that are often overlooked and underserved. We know that clinicians and researchers play a critical role in ensuring these individuals receive the best possible care, so we aim to support and advance new clinical and scientific leaders in these fields.

- [Uplifting Athletes Underrepresented Researchers in Medicine:](#) Agios sponsored the Uplifting Athletes Young Investigator Draft — Underrepresented Researchers in Medicine Initiative. The program is designed to inspire the next generation of rare disease researchers, leaders, and advocates; engage with and celebrate young rare disease researchers from underrepresented backgrounds; drive increased diversity in medicine; and ensure that rare disease patients from all walks of life feel represented by the researchers who are advancing innovations in their disease.



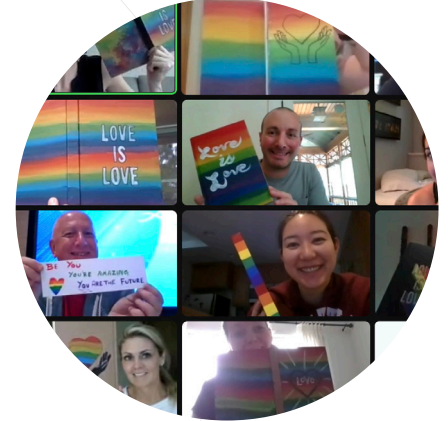
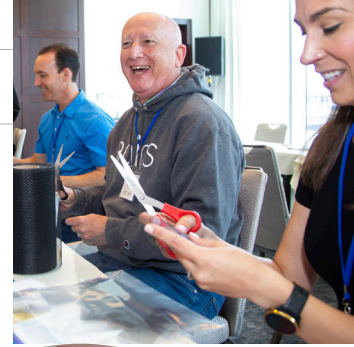
## Community Involvement

### Charitable Giving

Agios is committed to being a good neighbor in our communities, helping to meet the fundamental needs around us, promoting health and science, supporting people living with rare diseases and advancing opportunity for all regardless of socioeconomic status, race, gender or other factors that have historically limited opportunity.

We maintain a corporate giving program that identifies initiatives to support and creates opportunities for employee involvement in these causes that benefit our community. 2023 highlights included:

- Through partnership with the [Caring for Children Foundation](#), the Agios team donated and wrapped holiday gifts for 100 children whose families are facing life-threatening or life-limiting illnesses.
- Provided \$10,000 in corporate giving donations to [Life Science Cares](#) to further the organization's mission to make a difference on issues of poverty for our neighbors while helping life sciences companies build connections with the community.
- Sponsored the [International Institute of New England's](#) annual International Women's Day event, honoring immigrant women and daughters of immigrants who have made a profound difference in New England and the world.
- Provided \$10,000 to support the [Uplifting Athletes](#) Underrepresented Researchers in Medicine Initiative, which is designed to inspire the next generation of rare disease researchers and drive diversity in medicine.
- Donated more than 350 laptops to the [Hendricks Foundation](#), a non-profit that helps bridge the digital divide and reduce e-waste by providing repaired and updated technology to children to support their education.





## ↓ Community *Involvement* (continued)

### *Supporting Clinical Communities*

*Provided more than \$600,000 in unrestricted medical education grants* to support healthcare provider education and disease awareness, including continuing medical education (CME) programs.

*Awarded the Agios Hemolytic Anemias Clinical Fellowship Grant for \$75,000* intended to increase the number of skilled clinicians committed to providing comprehensive care for individuals living with classical hematological disorders with a focus on hereditary hemolytic anemias.

See [case study](#) on partnering with clinicians to improve patient care globally.

### *Supporting Patient Communities*

*Provided more than \$500,000 in sponsorships and memberships* to support conferences, disease education, clinical trial awareness, community building, and other initiatives led by patient advocacy groups.

*Provided \$100,000 in charitable donations to advocacy groups* dedicated to sickle cell disease, thalassemia, and PK deficiency.

### *Highlights*

*Held global leadership breakfast meeting with the Thalassemia International Federation (TIF)*

in Malaysia to discuss collaborative disease education opportunities.

*Collaborated with Cooley's Anemia Foundation to record a live podcast*

featuring a panel of teenagers with thalassemia at the Foundation's Annual Family Conference.

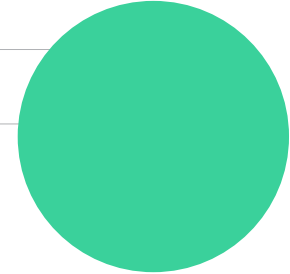
[Tune in](#)

*Provided a charitable donation to support the 'Nod to Naz' Art Exhibit,*

featuring a retrospective of work by the late sickle cell warrior, Hertz Nazaire.

See [case study](#) on advancing care for an underserved patient population.





## ↓ Energy and *Greenhouse Gas Emissions*

### *Energy and Emissions Reduction Efforts*

Although Agios leases all of our buildings, we continue to enhance and promote sustainable practices in our existing spaces and ensure our future spaces are designed with sustainability in mind. To date, we have completed a number of sustainability projects such as building a 50+ bike storage unit to encourage employees to cycle to work, conducting a lab renovation project utilizing energy efficient cold storage equipment, and updating our LED lighting technologies.

## ↓ *Environmental Stewardship* and Corporate Responsibility

### *Efforts to Reduce Hazardous Waste Production*

Our hazardous waste program ensures that Agios complies with all relevant local, state and federal regulations for proper signage, storage, labeling, transporting and disposal of waste. Agios saw a significant reduction in hazardous and non-hazardous waste volumes year-over-year in 2023 through implementation of waste minimization practices including improved chemical inventory management, waste stream auditing, and strategic waste packaging selection.

### *Sustainability Partnerships*

In alignment with our commitments to sustainability and charitable giving, Agios seeks opportunities to divert waste from lab and office equipment through donation whenever possible. In 2023, Agios coordinated donations of laboratory equipment and supplies; donated more than 350 laptops to the Hendricks Foundation, a non-profit that helps bridge the digital divide and reduce e-waste by providing repaired and updated technology to children to support their education; and organized a donation drive for prescription safety glasses.

### *Efforts to Reduce Solid Waste and Water Usage*

Agios continues to explore additional opportunities to reduce enterprise-wide consumption of single-use plastics. To date, we have saved over 140,000 plastic bottles from being landfilled. Through diligent monitoring of our water usage, Agios saw a significant reduction in laboratory wastewater volumes year-over-year in 2023.

Agios implements single-stream recycling programs and pipette tip recycling throughout the labs. Agios continues to compost as a main strategy for reducing waste. We use all compostable products in our cafeteria.



# Our Commitment *to Ethical Business Practices*

At Agios, we are committed to conducting business ethically, responsibly and transparently. We hold ourselves to the highest standards and have built strong governance practices to ensure accountability for our actions.



**2022 Cohn-Reznick**  
*ESG Gamechanger  
to Watch*



**2020 Women on Boards**  
*Winning "W" Company*



## ↓ Oversight of *Sustainability Practices*

### *ESG Working Group*

Our ESG working group is a cross-functional group of individuals representing the entire organization, including team members from clinical development, market access, human resources, legal, information technology, facilities, technical operations and external communications. This group is led by the Director of Corporate Communications and overseen by the Chief Financial Officer, who together provide updates to the Agios executive leadership team and Board of Directors.

### *ESG Oversight by the Board of Directors*

Our Board receives updates on ESG and sustainability at Agios. Updates come from the CEO, CFO, Head of Facilities and Director of Corporate Communications. In addition, the Board receives regular updates on human capital management from our Chief People Officer.





## ↓ Ethical Business Practices and Marketing

### *Description of code of ethics governing promotion of off-label use of products*

SASB: HC-BP-270A.2

Our business practices must be ethical, reflect our values, and adhere to all applicable local laws, regulations, industry codes, and guidelines. Our Code of Business Conduct & Ethics and policies are designed to support these values, among which is a commitment to the honest and truthful promotion and marketing of our products by:

- Only promoting Agios products after the necessary marketing authorization and only for approved indications
- Only using accurate and well-balanced scientific information in all of our marketing activities
- Responding to unsolicited requests for information about unapproved uses of Agios products in accordance with our policies
- Appropriately engaging with healthcare professionals and internal colleagues

We conduct regular training of our employees on applicable laws and policies. Agios sales representatives are appropriately incentivized and trained on the products they promote and responsible marketing practices. We encourage our employees to ask questions about any

activity that may present risk or seek advice about interpretation and best application of our policies and other elements of our compliance program. Our employees, officers and directors are also expected to promptly report potential, suspected, planned or actual violations of our policies and guidelines or applicable laws that govern our activities.

### *Description of code of ethics governing interactions with health care professionals*

SASB: HC-BP-510A.2

Given that healthcare professionals are often in a position to prescribe, recommend, purchase, supply, administer, or promote Agios' products, Agios places a strong emphasis on ensuring that its arrangements and communications with healthcare providers are appropriate, not intended to interfere with the integrity of those decisions, and comply with applicable laws, regulations, and industry codes and guidelines. Agios's healthcare compliance policies establish consistent global standards for Agios' interactions with healthcare professionals and healthcare organizations. Agios prohibits bribery and other corrupt conduct in any form. Bribery, kickbacks, and other improper inducements involving healthcare professionals, government officials, and others in the commercial marketplace, such as

customers, competitors, and suppliers, are prohibited. We require all relevant employees to complete compliance onboarding and regular retraining with respect to our policies. Under the direction of the compliance officer, Agios's Compliance function develops work plans and executes monitoring and auditing efforts to help identify compliance risk areas or matters that require further review or investigation. The Compliance team has direct access to Agios's leadership team, and reports to the Board of Directors and its committees on the implementation, operation, and needs of the compliance program.

### *Total amount of monetary losses as a result of legal proceedings associated with false marketing claims*

SASB: HC-BP-270A.1

None.

### *Total amount of monetary losses as a result of legal proceedings associated with corruption and bribery*

SASB: HC-BP-510A.1

None.

## ↓ Data Security and *Privacy*

### Protection of Personal and Patient Data

Agios is committed to processing personal data in compliance with applicable laws and in accordance with the principles below. In particular, all activities involving the collection and use of patient information must adhere to applicable privacy laws and patient authorizations or consents. Agios is respectful of patient privacy and has processes in place to protect the confidentiality of personal health information.

#### *Transparency*

When acting as a Data Controller, Agios will inform individuals whose personal data will be processed of the details of such processing through a Privacy Notice. In addition, where required by applicable laws, we will obtain consent prior to processing personal data.

#### *Limitation of Data Collection*

Agios only processes personal data that are relevant and not excessive for the legitimate business purposes specified in the privacy notice provided to data subjects.

#### *Data Integrity*

Agios takes reasonable steps to ensure that personal data are accurate and up to date. We will promptly update or correct inaccurate personal data or, if necessary, erase such personal data.

#### *Information Security*

Agios takes reasonable and appropriate precautions to protect personal data in its possession from loss, misuse, unauthorized access and disclosure, alteration and destruction.

#### *Data Subject Rights*

Agios respects the rights of individuals to request access, rectification, erasure, restriction and portability of their personal data, or to object to its processing, as provided by applicable laws.

#### *Disclosure to Third Parties*

Agios binds all vendors or other third parties who process data on behalf of Agios by contract to appropriate standards for the processing and safeguarding of personal data.

## ↓ Data Security and *Privacy* (continued)

### Cybersecurity and Privacy Program

Agios maintains a cybersecurity strategy that is based on four fundamental areas: Policy, Procedure, People and Technology. The Audit Committee of our Board of Directors is briefed on our cybersecurity program periodically throughout the year.

Agios maintains several policies and procedures that describe our employees' responsibilities for accessing computerized systems, handling of data and information and reporting cybersecurity events in a timely manner. Formal training on all policies and procedures relating to acceptable use, reporting lost or stolen equipment, password policy, access to computerized systems and reporting cybersecurity incidents is required by all employees and contractors.

Our Cybersecurity Incident Management Process is used to handle all levels of cybersecurity incidents. Incidents are categorized by severity, impact and risk and tracked for resolution.

### 2023 Highlights

- Successfully launched an enterprise-wide Third-Party Risk Management (TPRM) program, assessing all third parties for criticality and risk pre-contract; ensuring we hold our critical service providers to the same high standards and values held by Agios.
- Completed multi-year Disaster Recovery program, with routine testing and well-documented procedures, ensuring recoverability of critical infrastructure platforms and Agios-hosted applications.
- Enhanced cybersecurity training for employees and contractors, including instructor-led Phishing training. Routine 'Phishing' testing and retraining reinforce awareness, security and cyber-safety.
- Successfully executed third-party external and internal penetration tests, along with "Purple Team" tabletop exercises, to stay ahead of cybersecurity threats in an ever-evolving threat landscape.
- Implemented records retention schedules for email and Microsoft Teams Chat.



Policy



Procedure



People



Technology



## Corporate Governance *Highlights*

### *Code of Conduct*

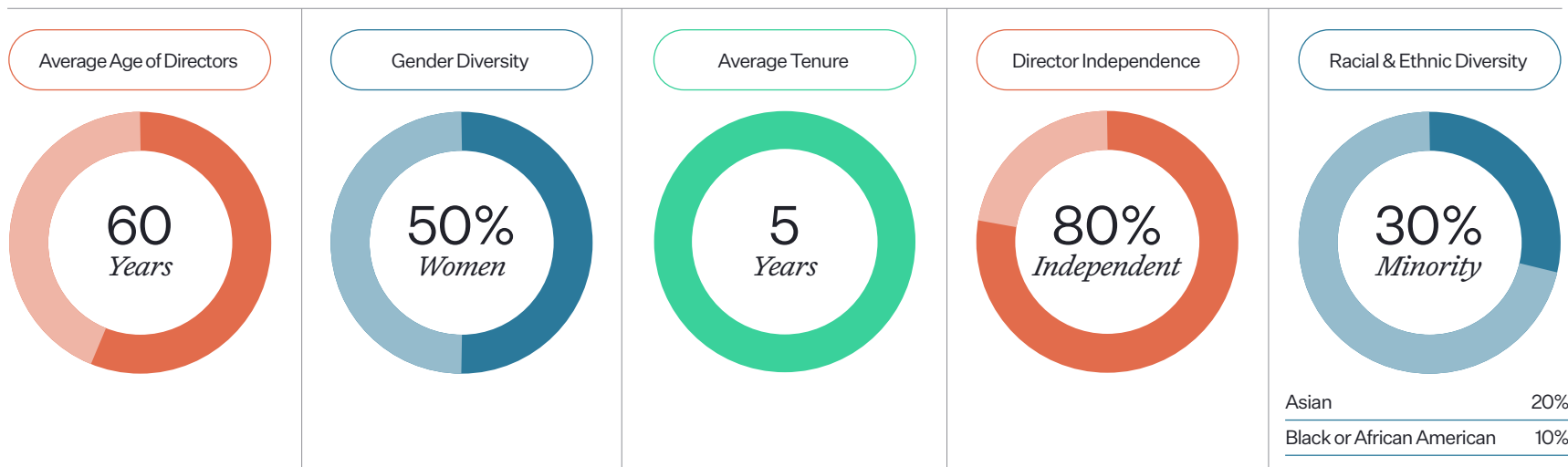
We believe that good corporate governance is important to ensure that Agios is managed for the long-term benefit of our stockholders. We have adopted a [Code of Business Conduct and Ethics](#), which applies to all of our officers, directors and employees.

### *Board of Directors*

Our board of directors has adopted [corporate governance guidelines](#), as well as charters for our audit committee, compensation and people committee, nominating and governance committee and science and technology committee, to assist in the exercise of its duties and responsibilities and to serve the best interests of Agios and our stockholders.

*These guidelines, which provide a framework for the conduct of our board’s business, provide that:*

- Our board’s principal responsibility is to oversee the management of Agios, and, in so doing, serve the best interests of the company and its stockholders, while considering the impact on other stakeholders including patients, the healthcare system and the our employees
- A majority of the members of our board shall be independent directors
- The independent directors meet regularly in executive session
- Directors have full and free access to management and, as necessary and appropriate, independent advisors
- New directors participate in an orientation program and all directors are expected to participate in continuing director education on an ongoing basis
- Our board and its committees will conduct a self-evaluation periodically to determine whether they are functioning effectively



## Corporate Governance *Highlights* (continued)

### *Best Practices*

- Shareholder engagement program
- Diverse board
- Board oversight of ESG
- Board oversight of corporate strategy and risk
- Stock ownership guidelines for executive officers and directors
- Continuing education for directors and orientating for new directors
- Mandatory retirement age of 75

### *Independence*

- Separated CEO and Chair Role
- Independent Lead Director with delineated responsibilities
- 100% independence among standing members of audit, compensation and nominating and corporate governance committees

### *Accountability*

- Regular Board and Committee self-evaluation
- Annual evaluation of CEO by independent directors
- Clawback policy
- Resignation policy

### *Shareholder Rights*

- No poison pill
- One-share, one-vote
- No dual-class common stock

## ↓ Safe Harbor *Statement*

This communication contains forward-looking statements within the meaning of The Private Securities Litigation Reform Act of 1995. These statements are based upon the current beliefs and expectations of Agios and are subject to significant risks and uncertainties. For example, there can be no guarantee that development of any of Agios' product candidates will successfully commence or continue, and there can be no guarantee that any positive developments in Agios' business will result in stock price appreciation. If underlying assumptions prove inaccurate or risks or uncertainties materialize, actual results may differ materially from those set forth in the forward-looking statements. Risks and uncertainties include, but are not limited to, those related to the impact of pandemics or other public health emergencies to Agios' business, operations, strategy, goals and anticipated milestones, including its ongoing and planned research activities, ability to conduct ongoing and planned clinical trials, clinical supply of current or future drug candidates, commercial supply of current or future approved products, and launching, marketing and selling current or future approved products; Agios' results of clinical trials and preclinical studies, including subsequent analysis of existing data and new data received from ongoing and future studies; the content and timing of decisions made by the U.S. FDA, the EMA or other regulatory authorities, investigational review boards at clinical trial sites and publication review bodies; Agios' ability to obtain and maintain requisite regulatory approvals and to enroll patients in its planned clinical trials; unplanned cash requirements and expenditures; competitive factors; Agios' ability to obtain, maintain and enforce patent and other intellectual property protection for any product candidates it is developing; Agios' ability to establish and maintain key collaborations; uncertainty regarding any milestone or royalty payments related to the sale of its oncology business or its in-licensing of Tmprss6 siRNA, and the uncertainty of the timing of any such payments; uncertainty of the results and effectiveness of the use of Agios' cash and cash equivalents; and general economic and market conditions. These and other risks are described in greater detail under the caption "Risk Factors" included in Agios' public filings with the Securities and Exchange Commission. Any forward-looking statements contained in this communication speak only as of the date hereof, and Agios expressly disclaims any obligation to update any forward-looking statements, whether as a result of new information, future events or otherwise, except as required by law.



Tobias, living with thalassemia



*Corporate Headquarters*

AgiOS Pharmaceuticals, Inc.  
88 Sidney Street  
Cambridge, MA 02139-4169

[www.agios.com](http://www.agios.com)



Ryan,  
living with thalassemia

