

November 2022

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Note from Elizabeth (EJ) Ashbourne, PQMD Executive Director



Happy November! I hope everyone had the opportunity to spend time with family and friends over the recent holiday. I must say, I am so grateful to be part of this amazing organization and among peers who contribute to creating a healthier and more equitable world through medical donations and health systems strengthening.

During this very busy month, I have a few exciting items to report. I'm thrilled to welcome our two newest members: Seeding Labs and Vertex Pharmaceuticals. They both will contribute greatly to our impressive network and provide valuable perspective rooted in the innovative work they are doing. Learn more about our newest members in the newsletter below.

As many of you know, we are close to completing Phase I of the GARDaccess initiative. We have created a new [website](#) where you can find the much-anticipated [guidelines](#) once they are released. Both resources will move forward the goals of the GARDaccess initiative to develop a Framework and a set of guidelines to ensure safe and quality products and services for patients with rare disorders globally. Additionally, we have drafted out, and developed a coalition of expert organizations, companies, NGOs, and patient groups, all contributing to the formation of a strategic, integrated operating model for global access to rare disease therapies.

This initiative is making strides to accelerate patient access to quality medicines, treatments, and services for rare diseases by harnessing the collective expertise of partners with shared values. To learn more about GARDaccess, you can now view the [recording](#) from PQMD's Pillar Talk Webinar: Rare Diseases: Challenges in Accessing Medicines.

And finally, I was also able to take a short trip to meet with some of our European members to discuss the agenda and programming for our Global Health Policy Forum in Paris this coming April. Our discussions were very fruitful, and I look forward to sharing the agenda and more information about the Forum soon. If you haven't yet, mark your calendars now to save the dates for April 24-27, 2023

I'm so fortunate to work with all of you! Stay safe and healthy.





PQMD Welcomes Two New Members: Vertex Pharmaceuticals and Seeding Labs

PQMD is excited to welcome two new members: Vertex and Seeding Labs to our distinguished membership. Both organizations will provide much needed perspectives into PQMD's mission and goals to provide high quality medical donations and promote sustainable access to quality health care in underserved communities and populations in crisis.

Vertex Pharmaceuticals invests in scientific innovation to create transformative medicines for people with serious diseases with a focus on specialty markets. Learn more about Vertex Pharmaceuticals [here](#).

Seeding Labs is a US-based nonprofit that is empowering every scientist to transform the world. We strengthen global health and science hubs in developing countries and help students around the world get a hands-on STEM education. More than 200 public and private sector partners have joined us in supporting 98 universities and institutions in 38 countries to train 25,000+ students each year. Our Instrumental Access program advances research on pandemic preparedness, health, energy, and the environment. Learn more about Seeding Labs [here](#).

To see the full list of PQMD members, visit our [website](#).



PROJECT TIMELINE - PHASE ONE



Project Contacts:

Guidelines Workstream
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Framework Workstream
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THANK YOU TO OUR SUPPORTERS!



GARDaccess Initiative Update

The first phase of the GARDaccess initiative is coming to a close. To date, two important documents have been completed. The first document outlines the operational framework for a secretariat that will manage and administer the alliance of rare disease stakeholders and partners. The second document details the quality standard Guidelines for assessing the needs, developing strategies, implementation planning and monitoring and evaluation of access to medicine programs specific for rare diseases in LMIC. Both documents will be available on the new GARDaccess [website](#).

Over the next months, the GARDaccess team will continue to refine the details of the activities for Phase 2 through engagement and in-depth dialog with prospective funders and other expert stakeholders in rare diseases and global health. The feedback will inform the ongoing development of the funding proposal.

If you have any questions about this initiative, please contact [Harpreet Ram](#).

SAVE THE DATES!



PQMD
Partnership for Quality
Medical Donations

**2023 Global Health
Policy Forum**

April 24-27, 2023
Paris, France

Learn about our Forums at pqmd.org

Stay Informed!

Be sure to follow us on [LinkedIn](#) or one of our other social channels to get the latest, most up-to-date information on our Pillar Talks, courses, events, and resources.



MEASURING FOR SUCCESS

PQMD Monitoring, Evaluation and Learning Survey Results

In a recent survey of PQMD members we asked members to share reflections about significant developments in their organizations monitoring, evaluation and learning practices over the past year. Here's what we heard:

- Members are developing, streamlining and deepening M&E frameworks as their strategies related to donations shift - this is true at an organization and program level
- Monitoring & evaluation systems are becoming more sophisticated, yet practical - and members are excited for growth including engagement of a wider group of invested stakeholders
- Algorithms to articulate the number people impacted through donated medicines continue to be a high area of interest and investment of time and talent
- Our members shared that they are partnering with academic institutions for M&E projects
- Our members indicated growth towards renewed consistency and quality of their MEAL systems following the shrinkage of these efforts during the pandemic

PQMD is so excited to expand our M&E network - please [reach out](#) if you'd like to learn more about our Measuring for Success Programs.

COMMUNITY OF PRACTICE



Rare Diseases: Challenges in Accessing Medicines

November 8, 2022 • 10:00 am EST



Sara Aswegan
Vice President and Chief
of Staff, Rare Disease,
UCB



Harpreet Ram
President,
EVR Consulting



Durhane Wong-Rieger
President & CEO,
Canadian Organization
for Rare Disorders



PQMD holds Pillar Talk: Rare Diseases: Challenges in Accessing Medicines- Recording Now Available

Rare genetic disorders collectively impact a significant portion of the world's population. Although individually rare, collectively the 7,000+ rare disorders impact 400 million individuals worldwide. Access to life-saving medicine programs in low- and middle-income countries (LMIC) presents a significant unmet need for patients living with rare disorders. For these individuals, challenges are further compounded by the paucity of diagnostic resources in a frail healthcare infrastructure, limited clinician access to rare disease educational programs, and limited or no access to life-saving medications due to lack of accessibility, affordability, and/or availability. There is a need to accelerate patient access to quality medicines, treatments, and services for rare diseases by harnessing the collective expertise of partners with shared values.

On November 8th, PQMD held the Pillar Talk – Rare Diseases: Challenges in Accessing Medicine to learn more how industry and patient advocacy groups and experts are tackling these challenges and working to form the Global Alliance for Rare Disorders Access (GARDaccess) – a patient-centric alliance whereby everyone contributes in a meaningful way, shares a united voice, and cross-collaborates. Through the development of a set of guidelines to ensure safe and quality products and services for patients with rare disorders globally and the formation of a strategic, integrated operating model for global access to rare disease therapies, the mission of GARDaccess is to bring hope and promise to individuals living in LMICs by providing seamless access to life-saving therapies.

[View Recording](#)





PQMD Coffee Chat: Medical Product Donations Gold Standard: Produce to Give and Manufacture to Donate

Produce to Give and Manufacture to Donate programs are often considered the Gold Standard in Medical Product Donations. These donation pathways represent a targeted, purposeful and often collaborative resource-intensive effort between manufacturers and implementers. Donations are made specifically in support of a set of clearly defined goals and are often disease, population, partner or program specific and support prepositioning for disaster relief response. Typically, these efforts proactively involve stakeholders and partnerships across sectors and often are aligned with global efforts to reduce, control, or eliminate a particular disease. Produce-to-Give/ Manufacture to Donate are often strategies that are used for corporate “signature programs” and tend to be time-bound and incorporate key milestones and opportunities for tracking success.

While, per our benchmarking data, 47% of PQMD corporate members maintain Produce-to-Give/Manufacture to Donate programs have you wondered what stars aligned to kick-them off and what resources and buy-in are necessary to keep them going?

During the coffee chat on November 15th, PQMD members from industry leaders Baxter and J&J shared their perspectives and guided a discussion to learn more about the internal processes that make these initiatives possible. Discussion topics included common practices, typical stakeholders, common vernacular alignment, processes, value propositions, trends, innovations, pitfalls/challenges and opportunities.



CoP Disaster Coordination Mechanism for Members

When disasters strike around the world, PQMD members are often on the front lines delivering lifesaving medicines and providing immediate relief to the affected populations. Coordinating these efforts is key to an impactful response.

[PQMD's Community of Practice Members Only Disaster and Response Discussion section](#) offers members a platform to post current and up-to-date response information including but not limited to: sitreps, needs lists, coordination all-calls and recordings, funding opportunities, and logistical information. You can also access an information and resource sharing platform for PQMD Members and their colleagues responding to the Ukraine crisis [here](#).

This real-time platform can streamline efforts, expand equitable response rates, increase the impact of limited resources, and ultimately improve the rate and capacity of delivering critical medical support to those who need it most.



MEMBER NEWS



access to medicine Index

World Sight Day: Partnerships to prevent trachoma in Tanzania

As IMA World Health recognized World Sight Day on October 13th, they honored their critical partnerships that are advancing efforts to control and eliminate trachoma, the world's leading infectious cause of preventable blindness.

Trachoma is a neglected tropical disease (NTD) and a public health problem in 44 countries. As of June 2021, 136 million people were living in trachoma endemic areas, including in many countries where IMA World Health operates. Blindness from trachoma is irreversible, and the World Health Organization (WHO) estimates 1.9 million people have been left visually impaired or blind as a result of trachoma infection.

IMA World Health began working to eliminate trachoma in 2009, providing antibiotics through mass distribution campaigns to millions of people annually in trachoma endemic areas of Tanzania. Following the guidelines of the WHO-endorsed SAFE (Surgery, Antibiotics, Facial Cleanliness and Environmental Improvements) strategy to prevent, control and eliminate trachoma by addressing its root causes, IMA World Health continues to address the backlog of TT cases. Working alongside the Tanzanian Ministry of Health, IMA has supported health system strengthening from the local to the national level while identifying patients and providing surgical interventions in hard-to-reach locations. By partnering with government-sponsored clinics and tapping into faith-based networks, IMA World Health has been able to reach the most remote settings with life-altering interventions to preserve sight.

To read the full article, visit IMA World Health's website [here](#).

The Center for Disaster Philanthropy Releases 9th Edition of the Measuring the State of Disaster Philanthropy: PQMD Members make Top 20 Index

The Center for Disaster Philanthropy has launched the ninth edition of the Measuring the State of Disaster Philanthropy report today. Based on the latest available data, the report documents nearly \$121 billion in private, public, corporate and individual disaster-related giving in 2020.

As expected, COVID-19 giving shattered disaster philanthropy records and dominated funding in 2020. But the report also highlights that only a fraction of disaster-related funding went toward other climate-related disasters and humanitarian emergencies that affected millions of people that year. These other crises include the record-breaking 2020 Atlantic hurricane season, Australia's "Black Summer," California's most destructive wildfire season ever and devastating droughts in Africa – just to name a few.

The 2022 Index finds that more companies have stepped up to address access to medicine in low- and middle-income countries, although there is stagnation in some key areas. PQMD members GSK, Johnson & Johnson, and AstraZeneca have emerged as clear leaders.

Also, on the top 20 include PQMD members: Merck, Pfizer, Takeda, Sanofi, Boehringer Ingelheim, Bristol Myers Squibb, Merck, AbbVie, and Eli Lilly and Company.

View the [Index](#) or download the [report](#).



Anera and Direct Relief deliver cancer medicines in Lebanon

There is currently a shortage of medications in Lebanon to treat cancer. Cancer patients in Lebanon are desperately chasing medications to treat their disease. This situation has unfortunately caused people to have to stop their treatment.

To help with the medicine shortage crisis in Lebanon, Anera and Direct Relief are delivering cancer medications to 1,100 patients with over 3,000 treatments. In total, Anera has delivered 5.4 million dollars-worth donated by Direct Relief to medical centers and NGOs throughout the country.

Watch Aneras' video [here](#).

GIVING TUESDAY

November 29th was Giving Tuesday! Please consider giving to our members.

Giving Tuesday is an opportunity for people around the world to come together through generosity in all its forms by sharing acts of kindness and giving their voice, time, money, goods, and advocacy to support communities and causes. Please consider giving to our members!

[Airlink](#)

[Americares](#)

[Anera](#)

[Brother's Brother Foundation](#)

[CMMB](#)

[ChildFund](#)

[Direct Relief](#)

[Heart to Heart International](#)

[HPIC](#)

[IHP](#)

[IMA World Health](#)

[International Medical Corps](#)

[IsraAid](#)

[MAP International](#)

[Medical Teams International](#)

[MedShare](#)

[Mercy Ships](#)

[Operation Smile](#)

[Project C.U.R.E.](#)

[Project Hope](#)

[Seeding Labs](#)

[The Max Foundation](#)

[UNICEF USA](#)

[USA for UNHCR](#)

[World Vision](#)

Learn more about Giving Tuesday [here](#).



[**Ethiopia's Tigray runs out of medical supplies amid health crisis: WHO**](#)

Reuters

[**Analysis: Tigray's largest hospital "doomed to collapse" soon due to lack of medical supplies, doctors warn as hospital death rate surpass ten percent**](#)

Addis Standard

[**Sanofi, Astra Drug Approved to Protect Infants from RSV in Europe**](#)

Bloomberg

[**COVID disrupted measles vaccinations in Africa and now cases are surging**](#)

Reuters

[**Ethiopian rivals agree on humanitarian access for war-ravaged Tigray**](#)

The Guardian

[**Report: Pharma firms must boost access for LMICs, R&D for pandemic threats**](#)

CIDRAP

[**African scientists say Western aid to fight pandemic is backfiring. Here's their plan**](#)

NPR

[**Dying too young: focus on communicable diseases take toll in South Africa's slums**](#)

The Guardian

[**Gates Foundation pledges \\$7 billion for Africa as Ukraine war diverts donor cash**](#)

Reuters

[**Search underway as magnitude- 5.6 earthquake leaves over 200 dead in Indonesia**](#)

CNN

Statement- Winter in Ukraine: people's health cannot be held hostage

WHO

Upcoming Events

**Data in Crises:
Discussions on Climate
Migration Driven by
Disasters**

December 8,
2022; 11am-12pm ET

**2023 Concordia
Americas Summit**

March 9-10, 2023; Miami,
Florida

**2023 Concordia
Americas Summit**

March 9-10, 2023; Miami,
Florida

**2023 PQMD Global
Health Policy Forum**

April 24-27, 2023; Paris,
France

*Does your organization have news to share?
Contact [Beth Haynes](#) for placement in future newsletters.
Next Month's Theme: Humanitarian Assistance*



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