**Title:** Developing a collaborative network for cystic fibrosis in Africa: A call to action

**Lay Title:** Working together to help children with cystic fibrosis in Africa

**Authors:** Leah Ratner a,k,\* , Hugues Abriel c , Muriel Helmers b , Ahmet Uluer a,f,k , R. Elaine Cagnina a,f,k , Chandra Swanson f,k , Grace Hennessy m,n , Abate Yeshidinber Weldetsadik i , Sheila Agyeiwaa Owusu j , Nada EL Makhzen c , Sandra Kwarteng Owusu g , Seyram M Wordui h , Annette Uwineza o , Samya Z. Nasrl , Marco Zampoli d,e

**Affiliations:**

A Brigham and Women’s Hospital, USA

b Department of Clinical Research (DCR), University of Bern, Switzerland

c Institute of Biochemistry and Molecular Medicine, University of Bern, Switzerland

d Division of Paediatric Pulmonology; University of Cape Town, South Africa

e Red Cross War Memorial Children’s Hospital, Cape Town, South Africa

f Boston Children’s Hospital, Boston, MA. USA

g School of Medical Science KNUST Kumasi Ghana, Ghana h Department of Child Health, Korle Bu Teaching Hospital, Accra, Ghana

i St Paul’s Hospital Millennium Medical College, Addis Ababa, Ethiopia j Department of Pediatrics and Child Health, University for Development Studies, Tamale, Ghana

k Harvard Medical School, USA l University of Michigan, Ann Arbor, MI, USA

m Imperial College School of Medicine, Imperial College London, UK

n School of Public Health, Imperial College London, UK

o Department of Biochemistry, Molecular Biology and Genetics, College of Medicine and Health Sciences, University of Rwanda, Rwanda, USA

**What was your research question?**

We know that there are children dying of Cystic Fibrosis in Africa, so we want to better understand how to help them. How do we start learning about cystic fibrosis in Africa? How do we build a team that can work together and share ideas? How do we do this with very little money?

**Why is this important?**

Cystic fibrosis, or CF, is a serious genetic disease that makes it hard to breathe, eat and grow. A genetic disease is something you are born with. It happens because of tiny changes in the instructions inside your body, called genes. These changes can make some parts of your body not work as well. CF is not yet well understood in Africa. This means some people get very sick or die. However, new medications are available in other countries that are allowing some children with CF to live long and healthy lives. We believe that every child born with CF, no matter where they are born, should have the same opportunities to live a long and healthy life.

**What did you do?**

We recognized that to solve this problem, we needed to gather a team of CF experts, doctors, scientists, and advocates from across Africa, and globally. We sent a message with specific questions in both English and French by email and WhatsApp. Given that we all come from different countries and backgrounds, people communicate through different languages and cultural contexts, so we also wanted to ask everyone how they wanted to communicate with each other and what they needed from the network to participate. After this, we had a big online meeting. People shared their problems and ideas for helping people with cystic fibrosis.

**What did you find?**

**Our from all over Africa (and the world) agreed that the five most important goals are:**

1. **Teamwork:** We need to work together as a team, bringing together different people, from different countries with different expertise.
2. **Spreading the Word:** We need to tell people about this sickness in ways that make sense for their culture, context and life. We need to listen to the children and their families that are living with this disease.
3. **Making a Big List (Registry):** We need to create one big list of all the patients in Africa (and what kinds of illness they have) so we can learn about the disease, from those who have it, in Africa.
4. **Teaching and Tools:** We need to train more doctors and nurses, and get good, low-cost tests for them to use, to help those living with the disease.
5. **Finding Funding (and global partnership):** We need to finance our work and find collaborators who want to partner with us from around the world.

**What does this mean and reasons for caution?**

**If we work together as a big team across Africa and the world, by sharing our knowledge and tools, we are better able to help people with CF.**

We are looking for **cheaper tests that** can help find patients early.

**However, we** have a lot more work to do. We only spoke to a small group of people. We need to talk to many more doctors and clinics in different places. **Join us in helping us grow, we need to:**

* Get **more doctors, nurses and researchers interested in joining us.**
* Find money (and resources) to pay for our work.
* Keep **listening** to the children and families who are living with cystic fibrosis. Their ideas are most important!

**What’s next?**

**We are looking forward to continuing to learn together. We are planning to help teach other doctors, nurses and researchers about CF. We are raising money for low-cost tests (sweat conductivity) to help diagnose patients and we are working together to build one big list (CF registry) of African patients. Most importantly, we are going to keep meeting and sharing ideas and help one another and those living with this disease in Africa.** **Come to our website**  [www.cysticfibrosisafrica.org](http://www.cysticfibrosisafrica.org) **to find out how you can help.**

**Original manuscript citation in PubMed**

<https://pubmed.ncbi.nlm.nih.gov/40914666/>