INVITED EDITORIAL

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Abstract

When it comes to global health, there is no 'them'... only 'us.' Global Health Council

There is a major anomaly in child health research. The majority of pediatric research resources and expertise is located in the developed world, whereas the vast majority of childhood disease and mortality is in the developing world. This disequilibrium has been referred to as the "10/90 gap", suggesting that only 10% of global health research dollars are devoted to conditions that account for 90% of the global disease burden (Global Forum for Health Research).

The Programme for Global Paediatric Research (PGPR) began as an effort to include, in a major pediatric research conference, topics dealing with diseases of children in the developing world in order to engage more interest and more research dollars. It has evolved into a program educating and linking professionals, and developing global networks of colleagues working collaboratively to solve major childhood health problems.

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PGPR began while I was the Editor-in-Chief of the international biomedical journal *Pediatric Research*. Towards the end of my five-year tenure in that position, we worked with the World Health Organization (Hinari program) to ensure that the web site of our journal (like other journals) was made available, without charge, to colleagues in developing countries. With that in place, I then reviewed the publications for which I had been responsible.

I was amazed and saddened to realize that of the more than 1000 articles published in *Pediatric Research* during my tenure, virtually none dealt with problems specific to children in the developing world. The same was true for the presentations at the major pediatric research meeting: the annual meeting of the Pediatric Academic Societies (PAS). Among the greater than 3000 abstracts submitted to the PAS meeting in 2003 few, if any, dealt with diseases primarily affecting children in low and mid-income countries. Indeed, my own research career had focused on hematology/oncology - on problems I encountered: Rh isoimmunization, the hematology of the newborn and the leukemias of Down Syndrome. Publications, meeting presentations and my own career spoke of a focus on diseases in "our" world without concern for the vast majority of childhood health problems. That was the way of academic pediatrics.

My "personal revelation" about the potential for pediatric expertise to help solve the problems of global childhood disease moved me beyond the path that I had pursued throughout my academic career. I discussed this issue with representatives of national and international pediatric societies as well as my col-

leagues in the Hospital for Sick Children. We agreed to establish a program that would further the involvement of pediatric clinicians and scientists in global child health research.

Accordingly, in January 2004, the Programme for Global Paediatric Research (www.globalpaediatricresearch.org) was established and based at the Hospital for Sick Children in Toronto.

The Programme for Global Paediatric Research Symposia and Workshops

We began by holding symposia and workshops at the annual PAS meeting (the largest meeting of pediatric researchers in the world). The PAS meeting is truly an international meeting, with researchers and clinicians from throughout the world. Over 200 attendees at the meeting are from Canada.

Our initial goal was to provide, at those meetings, a platform and profile for global child health research and issues needing to be addressed. In this way, we could interest and engage other experts at the meeting and they, in turn, might help solve the problems presented. The diseases and conditions discussed (i.e., pneumonia, neonatal asphyxia and infections and environmental hazards) cause the deaths of millions of children each year and the handicapping of millions more. Gradually, more presentations (in addition to PGPR presentations) on global health appeared in those PAS meetings. The progress from 2004 to 2011 has been gratifying and encouraging. In 2011, over 100 abstracts on global health were submitted to the PAS Meeting and over 40 scheduled lectures related to global child health. Thus, our initial goal is being realized.

That has been a "start" and PGPR intends to continue to hold symposia and workshops at the PAS meetings. It should be added that PGPR has also held sessions in Thailand, China, Benin and Ghana, as described on our web sites (www.globalpaediatricresearch.org and www.globalsicklelell disease.org).

Recognizing that many organizations (including NGOs, government agencies and pediatric societies) are responsible for developing and implementing global child health initiatives, PGPR began a few years ago to actively seek out these groups and include them in research workshops and other discussions in the hope that dialogue and collaborations will develop and flourish.

The PGPR Award for Outstanding Contributions to Global Child Health

PGPR has established an annual award to recognize distinguished contributions to global child health. This award in-

cludes a \$10,000 honorarium, and support to attend and present in the PGPR symposium held at the PAS Meeting. Recipients of the award have included Professor Zulfikar Bhutta (Aga Khan University, Karachi, Pakistan), Dr. Robert Black (Johns Hopkins School of Public Health, Baltimore, Md) and Professor César Victora, Emeritus Professor of Epidemiology, Department of Social Medicine, Faculty of Medicine, Universidade Federal de Pelotas, Brazil. Details of the awards are described on our web site (www.globalpaediatricresearch.org).

The PGPR Global Sickle Cell Disease Network

Innovative global networks of experts focused on particular issues have arisen from PGPR's larger, broader network. The first such "focused" network evolved from the vision of Dr. Isaac Odame, now a Director of the Sickle Cell Clinic at the Hospital for Sick Children. Dr. Odame met with me and discussed his grave concerns about Sickle Cell Disease (SCD) in Africa and in other low and mid-income countries. SCD is a terrible disease affecting millions of people in Africa and other developing regions. In Africa alone, approximately 300,000 babies are born with SCD each year. One half of those children will be dead by five years of age; the others live with the consequence of SCD (painful crises, pulmonary and other severe complications and progressive organ damage). With today's medicine and neonatal screening, few, if any, patients with SCD need die in the first five years of life.

Dr. Odame and I realized that there was a need for an international collaborative program for the study and care of patients with SCD. Further, we recognized the potential for PGPR to reach out to colleagues around the world to provide education about SCD. Preliminary meetings and discussions led to an international meeting in Cotonou, Republic of Benin [1]. That PGPR meeting included experts from many of the Sub-Saharan African countries, Brazil, France, England, USA, Canada and the Middle East. As a result of that meeting, and subsequent meetings and discussions, colleagues from these countries decided to form The Global SCD Network. The goals of the network include establishment of neonatal screening programs and of research to determine the scope of the sickle cell problem and to identify effective ways of treating the disease in low income countries. The Network intends to establish clinical and research coordinating care centres within Africa and other low and mid-income countries through which research can take place. These centres will facilitate local and regional training, infrastructure development, needs assessments and priority setting.

The Global SCD Network is an important example of researchers and clinicians from around the world working together to bring about real change that will not only have a positive impact on children born with SCD, but on whole communities and regions.

The PGPR Global Prevention of Kernicterus Network (Global PKN)

In PGPR's 2007 symposium at the PAS meeting, Dr. Tina Slusher presented a review of the incidence of severe neonatal jaundice and resulting brain damage (kernicterus) in developing countries. This issue has been highlighted in a recent publication [2].

Although newborn jaundice is common throughout the world, early recognition and treatment (phototherapy) prevents the development of brain damage (kernicterus) in most cases in developed countries. In fact, kernicterus is rare in developed countries (of the order of 1/100,000 deliveries), but much more common in developing countries. This inequity was the subject of a full PGPR symposium and workshop in May, 2009. That meeting resulted in the development of a world wide network of experts now known as The Global Prevention of Kernicterus Network (Global-PKN) that was established by, and is directed in collaboration with, Dr. Vinod Bhutani of Stanford University. Specific regional programs are being developed in India and China and plans are underway to develop programs in other parts of the world. The goals of the programs in these countries are to study and implement procedures for the recognition of neonatal jaundice and for the prevention of severe hyperbilirubinemia. Such procedures will likely include a data registry system, research to determine babies at risk as well as implementation and standardization of phototherapy.

Development of the Global PKN had an interesting and important effect on my own research. Early in my career I was involved in studies of Rh disease. Those studies contributed to the prevention of that disease so that in Canada, and in most other developed countries, the disease has been largely eradicated. Before its prevention, Rh disease was a major cause of severe neonatal jaundice, which, if untreated, could lead to kernicterus. When I was involved in planning the 2009 PGPR symposium on neonatal hyperbilirubinemia, I noticed there was no mention of Rh disease presumably because I, and most other experts in developed countries, believed that it had been "eradicated". A few weeks after the conference, I finally asked myself: "Has Rh disease been eradicated world wide?" Attempting to answer that question has led me, personally, on a new path of study.

Rh disease of the newborn is prevented by administering anti-Rh gamma globulin to women who have delivered an Rh positive baby; thereby preventing isoimmunization of the mother and Rh disease of subsequent Rh positive babies. Accordingly, I studied the distribution of anti-Rh (anti-D) gamma globulin world wide. Armed with that information, and knowing birth numbers and prevalence of Rh blood groups in each country, I was able to calculate how many women had received prophylaxis and conversely how many women were not treated [3]. The evidence indicated that each year more than one million Rh negative women in low and mid-income countries do not receive prophylaxis and, as a result, I can estimate that more than 100,000 babies annually are born with Rh hemolytic disease and suffer from its dire consequences.

This story is compelling because even I, directing a program for the study of childhood diseases in the developing world, initially did not recognize that a disease conquered in rich countries could still be a scourge in low-income countries.

Clearly, it is important to be ever-vigilant about any assumptions in global health.

PGPR helps to shed light on some of these assumptions and on the work that is still needed. It continues to contribute by focusing pediatric expertise on global maternal-child health issues through scientific meetings, collaboration with colleagues around the world and the creation of global networks for the study and care of childhood diseases.

References

1. Odame, I. Developing a global agenda for sickle cell disease: report of an international symposium and workshop in Cotonou, Republic of Benin. *Am. J. Prev. Med.* 2010; 38 (Suppl): S571-5
2. Slusher, TM, Zipursky, A, Bhutani, VK. A global need for affordable neonatal jaundice technologies. *Semin Perinatol* 2011;35: 185-191
3. Zipursky A, Paul VK. The global burden of Rh disease. *Arch Dis Child Fetal Neonatal Ed.* 2011;96(2):F 84-85.