



Newborn Screening IN POLAND A WELL-ORCHESTRATED SUCCESS

BY DONNA L. SCHILLINGER, ASSISTANT EDITOR



Not quite four years ago, Poland had no program for testing the hearing of newborns. Now the nation screens 99 percent of infants before they leave the hospital, an exemplary rate that establishes the former member of the communist block as a world leader. How did this impressive success occur, particularly so rapidly?

The process began a decade ago when the country had few proponents for newborn hearing screening. One among them was Dr. Henryk Skarzynski, a forward-thinking otolaryngologist who had a vision for a nationwide program. He initiated his plan by inviting international experts to come to Poland and conduct a series of lectures and training workshops.

Dr. Karl White, a top American authority on newborn screening from Utah State University, accepted Skarzynski's invitation to share his knowledge with the Polish attendees. Looking back on the experience, White reports, "Participants in the workshops learned quickly and were very enthusiastic. Subsequently, they were able to implement some small pilot programs but there were no resources to sustain them."

At the time, funding was unavailable for a variety of healthcare services, many of them to address the needs of newborns. Hearing screening was important but others, like pediatric cardiac care, were more critical.

The seeds of a national movement to remedy the shortfalls were already being sown by Dr. Bohdan Maruszewski. In 1992, the prominent pediatric heart surgeon from

The Children's Memorial Health Institute in Warsaw took it upon himself to find a solution to the health needs of Poland's infants. One of Maruszewski's first moves was to seek assistance from leading entertainment personality Jerzy Owsiak. The celebrity, known throughout Poland as Jurek, quickly came on board and used his popular television show to help raise funds.

The efforts of the doctor and talk show host raised \$1.5 million in donations. It was enough to equip all 10 of the country's cardio-surgery divisions to perform lifesaving operations on children with congenital heart defects.

The gratifying response to the appeal soon spawned a formal foundation, The Great Orchestra of Christmas Charity (GOCC). Jurek remains integrally involved as president of the board and GOCC's annual fundraiser has grown to be one whopping, daylong, nationwide affair.

The fundraising concept is simple: The first Sunday in January, the day that marks the end of the Polish Christmas season, tens of thousands of volunteers, mostly teenagers, take small collection boxes and go door to door asking for donations. In exchange, donors get a red heart to wear.

At the end of the day, almost everyone in the country of 40 million is sporting a red heart and the collection boxes are full of small donations. Totals are almost unbelievable – the January 2004 event brought in \$6,923,443!

Every summer, GOCC sponsors a free concert, Woodstock Stop, to thank donors and promote the program. Musicians donate their time and talents and costs associated with the concert are paid by corporate sponsors. Attendance numbers over 100,000 and the event is a top news story for days.

Each year since the initial 1992 fundraising event, GOCC identifies healthcare needs that could be significantly impacted with supplies and/or equipment and each year, the Polish people respond with greater contributions. To date, the charity has "invested" over \$50 million in the health of the nation, leading to an impressive list of accomplishments.

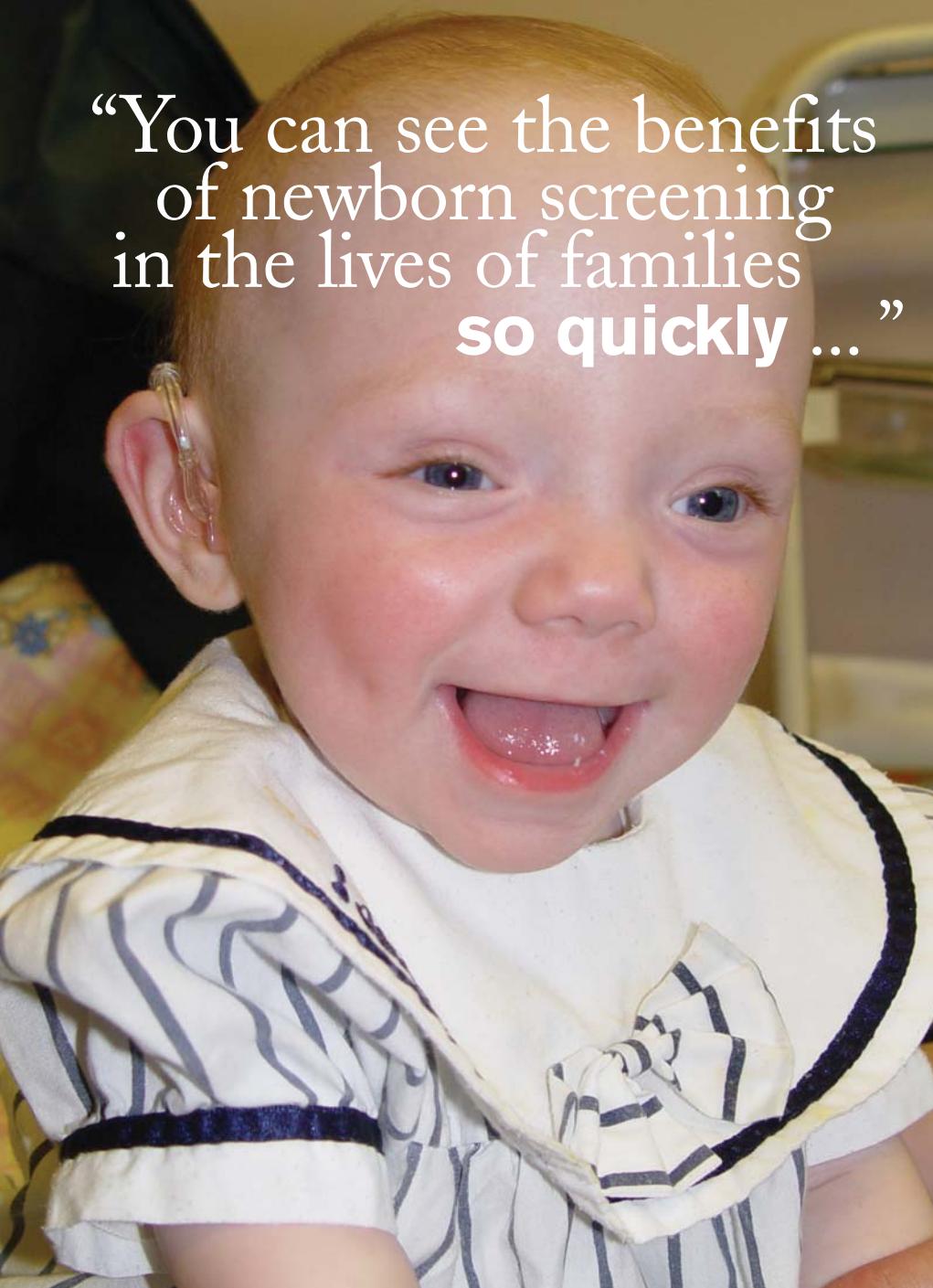


It has provided: medical equipment for numerous neonatal divisions, pediatric oncology divisions and hospices, post-traumatic surgery divisions and nephrology divisions; personal devices for home dialysis to all children on dialysis; and personal insulin pumps for children with diabetes. GOCC also runs first-aid training sessions in collaboration with the Polish Red Cross and has founded a diabetes center.

All the projects funded by GOCC were one-time causes that did not require ongoing support ... until the fall of 2000. That was when Dr. Marzanna Radziszewska-Konopka,

The proud staff of the Great Orchestra of Christmas Charity after their presentation at the International Conference on Newborn Hearing Screening in Italy in May. From left: Igor Tratkowski, Małgorzata Wisniewska Gontarek, Dorota Dunin Wasowicz, Jerzy Owsiak, Agnieszka Tratkowska, Ola Owsiak, Jacek Stachera and Grzegorz Chojnowski. Jurek displays one of the corporate sponsorship programs; a small percentage of each purchase with the GOCC Visa card is donated to the charity. OPPOSITE PAGE: A GOCC banner declaring "We will play till the end of the world ... and one day longer" decorates the Warsaw town hall high above a concert celebrating the charity's annual fundraiser. BELOW: The broadcast studio during this year's frenzied finale. PHOTOS COURTESY OF GOCC AND KARL WHITE





“You can see the benefits of newborn screening in the lives of families so quickly ...”

Victoria's hearing loss was discovered during newborn screening. Thanks to early detection and intervention, she is a happy beneficiary of Poland's generosity to GOCC.

head of audiology, phoniatrics and laryngology at The Children's Memorial Health Institute, entered the scene. She petitioned the charity to designate newborn hearing screening as the project for January 2001, which it did.

The ninth finale of the GOCC raised over \$6 million and Poland's infant screening program was born. Plus, breaking with its former funding protocol, the GOCC committed

to sustaining the program financially.

The primary reason for the change? White explains, “You can see the benefits of newborn screening in the lives of families so quickly that Jurek's group became really excited about it.”

Radziszewska-Konopka called again on White and others in the field, seeking assistance on implementing a program now that funding was available. White recalls that in their meeting, the Polish team informed him they intended to set up all of the nation's 440 hospitals to do newborn hearing screening within a 30-day period, a goal he thought unrealistic. But they did it!

“The Polish are the most amazing people I've ever worked with. They are competent, hard-working and creative. I'd rather do work in Poland than anywhere else because of the people,” adds the obviously impressed American.

White was recently invited to return to Poland as a special guest of the twelfth annual GOCC finale along with British and Italian newborn screening experts. Dr. Fernando Grandori of Italy told the finale audience, “No European country has been able to get a program running successfully in such a short time,” a phenomenon he too attributes to Polish enthusiasm and determination.

It seems the success of newborn screening also had an element of the right person being in the right place at the right time. Communism in Poland had fallen only three years prior to Jurek's initial fundraising effort. White believes that the atmosphere and people were ripe for burgeoning charitable efforts and Jurek's was one of the first.

“A lot of GOCC success is also attributable to the kind of person Jurek is,” White says. “He is one of the most enthusiastic people I have ever met. He donates his time to the foundation and has a very small staff which keeps overhead costs down.”

However, it is the dedication of everyone involved that makes GOCC thrive. Jurek included the word “orchestra” in the charity name to reflect the group effort. He believes that to have a society of happy and healthy children, everyone has to work together, each contributing unique strengths and abilities in the same way that instruments in an orchestra each sound differently but blend together in harmony to create something that none could alone.

Jurek's GOCC is now in negotiations to complete the transfer of the financial responsibility for newborn hearing screening to the Polish government. The Ministry of Health has agreed to assume the funding role but the transition will likely be gradual to ensure the ongoing success of a program that has had a very unique and auspicious beginning. ■