

## On Listening to What the Children Say

*By Al Freedman, Ph.D.*

In the ten years since my son, Jack, was diagnosed with Spinal Muscular Atrophy, a number of unanticipated and meaningful professional opportunities have come my way. For each of the past six years, I have led a workshop at the Families of SMA Conference called "Life After Diagnosis" for family members of newly diagnosed children. I have written and published articles for educational and medical publications, given speeches at professional meetings of health care professionals to groups as large as 900, consulted in health care and special educational settings, provided psychological services to many families of children with special needs, led group counseling sessions for nurses grieving the loss of pediatric patients, and participated on an advisory board at the children's hospital that provides care to my son.

While all of these experiences have been important and meaningful, the opportunity to facilitate a discussion group for SMA-affected children at this year's Families of SMA conference was a very special privilege to me, both professionally and personally. Up until the moment I arrived at the conference meeting room, I didn't know what to expect. Within a couple minutes, I was pleasantly surprised to find myself sitting in a circle with eighteen wonderful children representing 10 states and Canada. Three of the eighteen children who participated are ambulatory --- so it was the four of us without wheelchairs who were in the minority as we all sat together in a circle.

Because of the group's agreement that I would keep our discussion confidential, I am not able to share the details of our 90-minute session. However, I can say that once the children listened to a brief explanation of who I am and the purpose of our meeting, they were very eager to participate. First, the children introduced themselves by sharing their names, ages, and their hometowns. Like most children who come to my office for their first appointment, many of the kids in our group had mixed feelings about coming to the session. When I asked, many acknowledged it was not their own choice, but their parents' choice, to attend. They were relieved to know that most of Dr. Al's clients feel exactly the same way the first time I meet them.

As the children took turns speaking, I was impressed and touched by their honesty, thoughtfulness, intelligence, and kindness towards each other. Each of the children had something meaningful to say, and most contributed more than once. Some children posed questions and listened to ideas from their peers. I am quite sure the children would have continued talking with each other for at least another hour if offered the opportunity.

As the end of our session approached, I asked the children to think for a moment about a wish they have. We sat together in silence, reflecting on the conversation we had just experienced, as we all considered our wishes. Then each of the children spoke. I received the children's permission to share their wishes. What follows is a representative sample of what I heard the children say:

"I wish everyone would be nice to people in wheelchairs."

"I wish all of our families can be friends and see each other."

"I wish I could play sports normally and I wish I could walk just like everyone else."

"I wish that someday I can have a service dog."

"I wish we could find a way to show people we're really no different -- we're just as good as everyone else."

"I wish there weren't any diseases anywhere."

"I wish that everyone who says we're lucky (to have a power chair) could spend a week in my wheelchair."

"I wish that one day there will be no SMA."

"I wish that one day we will all be able to walk."

To all of the children who participated, thank you for sharing your thoughts and ideas with each other so openly and honestly. To all of the parents of the children who attended, thank you for the opportunity to get to know your children, and thank you for your trust in me. I look forward to offering additional sessions for children at future FSMA conferences.

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