



A Parent's Guide To Children's **HEARING LOSS**

WITH COMMUNITY RESOURCES IN CENTRAL OHIO

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FOREWORD

Finding out that your child is not perfectly healthy and has some medical illness is quite devastating. This is the case even if both parents are in the medical profession. Once you get over the “Why me?” and “Did I do something wrong?” or “It’s your/my fault”, going through the myriad of emotions including devastation, anger, confusion, sadness, helplessness, desperation, resolve, hope, and frustration, you are faced with the daunting challenge of navigating through the vast maze of healthcare system. As parents, my wife Kim-Jae and I experienced what this felt like twice, in two of our three children. They had different illnesses that were unusual and it took many months with multiple visits to multiple medical professionals to find out the diagnoses. Even after the diagnosis was made, we frequently found ourselves confused, feeling alone and frustrated about what it all meant and who and what was going to help us find our way through the health system to ensure that our children were getting what is the best for them. Although each medical professional was informative and many of the books and literature were helpful, we realized that there was a great need for comprehensive up-to-date guide that would provide the needed information to guide parents with children with various chronic illnesses.

When I retired after twenty years of the service in U.S. Navy Medical Corp, I began working at San Diego Children’s Hospital. I was able to set up one of only handful of State certified Pediatric Cochlear Implant program in California. My wife Kim-Jae, with her life time devotion of helping others through many years of volunteering and being keenly sensitive to the needs of parents, quickly pointed out how much need there was to provide support for these parents who have to deal with their infant’s devastating yet not well understood condition of being hard of hearing. Despite all of the recent technological advances in treatment of hearing loss such as cochlear implants, there is still no cure for sensorineural hearing loss – medical science presently is not able to restore the hearing to normal function. Sensorineural hearing loss is a lifelong problem that needs to be addressed medically and educationally, throughout a child’s school years into adulthood. With this understanding, Kim-Jae has provided me with many key ideas on how to best serve the family, much of which I would not have known or realized without her insight of being a mom and a woman. When I came to Columbus, Ohio in 2003 to head the Department of Otolaryngology at the Children’s Hospital, one of my objectives was to establish a program that provided comprehensive multidisciplinary services to children with hearing loss. I met with many in the Central Ohio community who were providing care for these children. They all told me that Central Ohio had a real need for the Children’s Hospital to take the lead in the community to establish a program that not only provides highest quality medical care but also provides the continuity of care in coordinating the services throughout the child’s life.

For parents, it is critical to be able to have some understanding of the information provided by the medical professionals so that they can feel comfortable being an advocate in seeking out the best care for their child. Most parents will soon realize that despite best intentions, presently our healthcare system frequently is not very parent or family friendly. The system has a ways to go to provide long term support for parents and families in dealing with children with chronic illnesses. The Medical Home model, introduced by the American Academy of Pediatrics in the 1960’s as a way of centralizing record keeping, was updated in 2002 to emphasize family-centered care that is accessible, comprehensive, continuous and coordinated. This model seems to be the ideal way to provide care for the children with chronic illness. From the parent’s perspective, they must have written resource(s) that helps them explain these concepts and provides the necessary information to guide them through their choices and responsibilities.

There are many resources available locally, regionally and nationally from hospitals and government agencies. Unfortunately for the Central Ohio parents with children who are hard of hearing, there has not been a single comprehensive written guide that is easily available for them. Working assiduously and tirelessly for close to a year, Kim-Jae has almost single handedly completed this needed comprehensive Parent's Guide that will help families with hearing loss children. Beginning with the shock of the initial diagnosis through the child's school years into young adulthood, parents can refer to this guide throughout the life long process of advocating for their child.

I wish my wife and I had this type of resource when we were dealing with the illness in our children. I think those of you who have gone through the process previously will have the same reaction and those who will be going through this in the future will be very appreciative knowing that now they have this resource.

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ACKNOWLEDGMENTS

Dr. Karen Heiser, Vice-President of Education Designated Institutional Official at Nationwide Children's Hospital understood the importance and our purpose of having this Parent's Guide for parents of children who are deaf and hard of hearing. Thank you for believing in my husband, D. Richard Kang and me and for allowing us to get this much needed information out to parents and professionals who work with children with hearing loss.

Marcie Rehmar, Director of Community Education was assigned to work with me. My gratitude to you for your support, input, and all your time spent in editing this Parent's Guide. I'll miss our scone and coffee meetings! Thank you to the Marketing department under the direction of Linda Gregory, Director of Branding & Consumer Marketing and all her staff including, Rachel Driskell for getting this out in print. A thank you also goes to Chris Garbrandt, Manager of Creative Services, and Abby Baird, Graphic Designer, for the superb job done in the layout of this Parent's Guide!

Special thanks to these individuals that have reviewed and given me their feedbacks in their specialty area: Marla Sarpotdar, Megan Reese, Jenny Monte, Laura Stanley, Dr. Kirstin Chiassin, Dr. Darryl Robbins, and Dr. D. Richard Kang.

I am grateful to Dr. Lyn Robertson who was willing to share her personal story and journey raising a child with hearing loss. Thank you for providing hope to families that their child has a bright future... "Your Future Can Be Full of Promise!"

Parents from Nationwide Children's Hospital Parent Advisory Board for parents of children with hearing loss and other parents reviewed and gave their inputs. Thank you for meeting with me and giving your feedbacks from a parent's point of view. Special appreciation is extended to all the families that I have personally worked with over the years for sharing their personal stories with me and for allowing me to be a small part of their lives!

I want to especially thank Michelle McCully who was more than willing to take the challenge to assist me in writing this Parent's Guide. We met over several months and spent countless hours working on this. A genuine "thank you" for your dedication and hard work in assisting me to do this and for all your endless support!

I also want to thank Megan Reese and Michelle McCully for their devotion and passion in advocating for families with children who are deaf and hard of hearing! Your passion is truly to be commended and should be role modeled by all professionals working in this field.

Lastly, from the bottom of my heart, I am deeply grateful to my husband, D. Richard Kang for believing in me that I could get this information out to parents in written form, trusting in me that I would get this accomplished, and encouraging me during the process of writing this Parent's Guide. Your support enabled me to bring this to completion! Your dedication to always putting children and families first and your expectation for your team of professionals to provide the *best care* possible serve as a source of inspiration and admiration for me. Your genuine concern and compassion for the families you work with, serves as a model to us all in trying to provide the *highest standard of care*.

My husband and I shared in the belief for the need for this Parent's Guide. It comes from our understanding of the devastation that parents feel when given the news that their child is deaf or hard of hearing and the parents' need to find appropriate resources to help their child. Parents have indicated to us the need for this Parent's Guide ... your voices were "heard"! This Parent's Guide provides the necessary information that helps parents learn about their child's diagnosis and the importance for getting appropriate early intervention services for their child.

We hope this comprehensive Parent's Guide will help you navigate step by step through the process of getting services needed to help your child. It provides information for parents to learn the process of getting medical and therapeutic early intervention for their child, from birth through their school years. Community service providers and resource directories are also included. The Parent's Guide can be referred to, over and over at various stages of their child's development and need for required services.

This Parent's Guide is *our gift* to you and your child and to all the dedicated professionals who strive diligently to continuously provide the very *best care* for children with hearing loss.

Kim-Jae O. Kang

We would be remiss if we did not extend a very special thank you to Kim-Jae Kang. It is Kim-Jae's vision and passion that made this guide possible. She spent countless hours researching, writing and proofing all fueled by her conviction to help parents who have a child with hearing loss with their journey. Kim-Jae, with heartfelt thanks and appreciation for this wonderful gift to the families of central Ohio. Working with you has been a pleasure.

To the many professionals in Clinical Therapies, Audiology and ENT who reviewed this guide to assure accurate content and the Marketing team for taking pages of copy and turning it into this beautiful book, many thanks. It is my hope that this resource will serve central Ohioans well in helping them make the choices that are best for their family.

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INTRODUCTION

“A Parent’s Guide to Children’s Hearing Loss” will help parents learn about their child’s hearing loss. It provides important information for parents to learn the process of receiving medical and therapeutic intervention for their child from birth through school age. Parents will learn about audiological tests, medical diagnosis and treatment options, early intervention, including choosing communication options, and education services required to help your child reach their full potential in hearing and speech and language development. A flowchart of the Early Hearing Detection and Intervention (EHDI) is in each section to help parents follow the step-by-step process of getting services for their child. Community service providers/resources and a directory of organizations are also provided. Additionally, personal comments from parents of children with hearing loss are featured throughout the Parent’s Guide.

SUMMARY OF SECTIONS

Below is a brief summary of each section in this Parent’s Guide.

I. EARLY HEARING DETECTION AND INTERVENTION

The Centers for Disease Control (CDC) recognizes hearing loss as the most common birth defect, affecting every 3 in 1,000 live births. In 2004, the state of Ohio adopted into law the Universal Newborn Hearing Screening (UNHS) to assure that all newborn babies have a hearing test before being discharged from the hospital. The Early Hearing Detection and Intervention (EHDI) states that a baby will receive screening before 1 month of age, detection before 3 months of age, and intervention by 6 months of age.

This section also explains the importance of the “Medical Home” model. The “Medical Home” model is used to coordinate the child’s medical care, which is a shared responsibility between the child’s primary care doctor and parents.

II. WHAT DO THE RESULTS MEAN?

All babies have their hearing screened at birth. The test results may indicate Pass or Non-pass/Refer. Pass means no more testing is required at this time unless your child/ family have additional risk factors. Non-pass/Refer means that your baby needs further testing by an audiologist.

III. THE FOLLOW-UP HEARING TEST

When a follow-up hearing evaluation has been completed by an audiologist and confirms your child has a hearing loss, results are sent to the Ohio Department of Health (ODH). ODH works with Centers for Disease Control (CDC) to keep records so that your child receives early intervention services. The specific roles of each professional; audiologist, the child's primary care doctor, ENT (Ear, Nose, & Throat) doctor, and ODH- Help Me Grow (HMG) and Regional Infant Hearing Program (RIHP) are discussed.

IV. MY CHILD HAS A HEARING LOSS "Our Lives Have Been Turned Upside Down!"

Parents often feel guilty and blame themselves for causing their child's hearing loss. This and other common reactions are discussed in this section. Parents will learn the importance of a support system, and how their support team will assist them in taking care of themselves, their child and their family. Researching and understanding their child's diagnosis will help parents make a plan of action from an informed decision making process to advocate for the needs of their child and family.

V. AUDIOLOGICAL TESTING

An overview of audiological (hearing) tests, are reviewed so that parents have a better understanding of the purpose and the importance of these tests.

VI. DIAGNOSIS – Causes/ Etiology of Hearing Loss

Hearing anatomy, types of hearing loss, degrees of hearing loss, and causes of hearing loss are discussed so that you can better understand your child's diagnosis.

VII. MEDICAL TREATMENT

Amplification and hearing technology; including hearing aids, implantable hearing aids, cochlear implant, and Assistive Listening Devices and Systems (ALDS) to optimize your child's hearing are discussed.

VIII. EARLY INTERVENTION

The importance of early intervention, speech and language development, and communication options are reviewed.

IX. EDUCATION SERVICES

This section explains the federal laws: Individuals with Disabilities Education Act (IDEA), Federal Funds under Part C and Part B, Individualized Education Plan (IEP) process, and the American Disabilities Act (ADA) for children with disabilities. These laws are reviewed to help parents learn and understand how to get education services for their child.

X. WHAT DOES THE FUTURE HOLD?

Final considerations and thoughts are shared, including a parent's personal story.

APPENDICES

Additional important information is included at the end of this Parent Guide.

RESOURCES

A list of community service providers/ resources for children with hearing loss is provided. Resource directory of national organizations are also included in this section.