NEW DIRECTIONS

Spring 2015

Early Childhood Direction Center
c/o Women and Children's Hospital
219 Bryant St.
Buffalo, NY 14222
PHONE (716) 880-3875 or
1 800 462-7653
FAX (716) 836-1252

Vickie Rubin
Manager
vrubin@kaleidahealth.org

Tracey Banks
Coordinator of Early Childhood Programs
tbanks@kaleidahealth.org

Ruth Malinowski
Special Needs Outreach Liaison
rmalinowski@kaleidahealth.org

Stacie Ricioppo
Special Needs Educator
sricioppo@kaleidahealth.org

Lauren Savino
Special Needs Outreach Liaison
lsavino@kaleidahealth.org

ECDC is a regional clearinghouse that provides free information, referral, technical assistance and support to families, professionals, and community agencies concerned with children birth to five with suspected or diagnosed delays or disabilities.

We provide ongoing community training programs for both parents and professionals.

ECDC is funded by the New York State Education Department, hosted by Women and Children's Hospital and provided in-kind support from People Inc.

If you would like to be included on our listserve to receive the latest federal, state and local updates, please send an email to ecdc@kaleidahealth.org and indicate whether you are a parent or a professional.

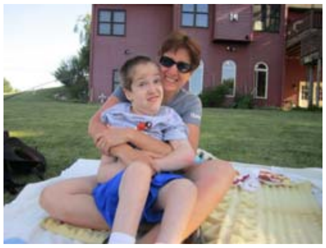
facebook join our group +

www.facebook.com/ECDCWNY1

When the Doctor Said My Son Would Only Make It to 4 Years Old

(One Mother's Story)

By Diane Blair



"He will live until about 4 years old."

Our doctor told us this when our son, Alex, was officially/unofficially diagnosed with Spinal Muscular Atrophy (SMA). Officially, because the doctor had experience with children born with SMA; unofficially, because the blood work hadn't yet come back confirming it. In a weird way, we thought ourselves lucky because the websites and local doctors knew that the majority of children born with type 1 SMA die before their second birthday. We thought: *We just doubled that!*

SMA is a form of Muscular Dystrophy. It affects the way a person crawls, sits, walks, breathes and swallows. About one in 50 people are genetic carriers. SMA can affect any race or gender. As time goes on, a child diagnosed with SMA will get weaker and lose any and all muscle function.

What would I tell myself at the time of diagnosis that I now know?

Doctors don't know everything.-Doctors cannot possibly know when someone will die because they often base their assumptions on what has happened in the past — not with the current research and knowledge that may still be forming. Parents of children with the same diagnoses as your child know *a lot.* Ask them everything you can – no question is a stupid question when it comes to your child. Children are fighters and have a way of proving us wrong.

Have faith.-Alex will be 12 years old in February. He's alive, goes to a regular school, has friends, loves everyone he meets and is a happy, curious, lovable kid.

Don't get me wrong, his life (or ours for that matter) has not been an easy one. He's been hospitalized three times but each time has been shorter than the last. He's had ear infections, colds lasting up to a month, pneumonia, paraflu, strep throat, C. diff, bacterial pneumonia, staph infection, a collapsed left lung, a fractured right femur, pneumonia again, sinus infection, back surgery and a fractured left femur. We know what to do when he gets sick and how to treat him at home. We have doctors in our corner who listen to us (and him) when needed. We also know things can change at any time and we must be prepared. We need to keep germs away because they're the enemy. It's not so much getting sick, it's the inability for his weak body to fight the germs. We try not to keep him in a bubble. He needs to experience life.

We were initially told to stay away from the Internet for information. Some information you receive is correct and some is not. Some can be dark and scary. If I had to give advice to a parent of a newly diagnosed child with special needs, it would be this:

Continued on Page 2

Continued from Page 1

- Have doctors in your corner who are willing to listen to you and your child — and if they don't have the answers you need, know they will find it for you. They must be able to reach out to other doctors who specialize in the care you're looking for. They must realize that they don't know everything. If you don't have a doctor where you live, find one elsewhere who knows what they're talking about.
- Connect yourself with parents who are also on the same journey as you and ask them questions — but know that even though the diagnosis is the same, they may do and say things you might not be comfortable with. You need to weigh your options with your beliefs and the needs of your family. Unfortunately, I've come across quite a few parents who are angry and they may lose sight of what is important. Everyone deals with the stress of a child with special needs in their own special way. If you don't understand where they're coming from, you can respect that and move on.
- I'd suggest seriously considering enrolling your child in a trial study if it's available. This is how the researchers find cures and/or treatments. This is how you can help future children and their families who may receive the devastating news. You may see your child as a guinea pig, but if you don't investigate the possibilities, who will?
- Have a little faith – chose your path to help you get through this. Miracles do happen.
- Love your child with all your heart and soul, and let them feel it.
- Try and have some time for yourself, your significant other and other children if you can. You don't even have to leave the house. See if you can get someone to help you out just to give you a little reprieve.
- If you're on information overload, take a step back and regroup.

We do the best we can with what we know and what will get us through this journey.

Everyday Things Can Be Therapy!

By: Lauren Savino, M.S. Ed.

There are many activities a parent can do with their child to support progress during early childhood. Sometimes a parent may feel lost or unsure of how to help their preschooler who may have developmental delays or a disability. Parents often think they must need to be a certified teacher or therapist to "teach" their child when truly there are so many things you can do to help with growth in the areas of Speech- Language, Learning, Self-Help, Physical and Social development. You can learn how to become your child's own teacher!

We are here to help! We created a complete list of activities with descriptions to help parents support their own child. Listed below is the first area that we are going to discuss, Communication or Speech Language. To find the entire document see the link at **http://www.wchob.org/ecdc**. These activities can be done at any point in the day in order to continue promoting development in your child.

#1: Speech Language Development

You do not need to be a Speech Therapist to help your child with communication. Children's language development improves when their parents become their own 'speech therapists'. There are many activities you can do as a parent to encourage speech-language development in your child.

Ask your child to:

- Listen to a story that you read. Ask them questions about the story.
- Name and label objects in your child's room, playroom, bathroom, kitchen etc.
- Talk about family photographs.
- Tell you about a TV program they like.
- Play 'Simon Says' making sure to name/ label body parts.
- Name fruits and vegetables.
- Tell you the names of family members.
- Talk about what he/she sees through the window.
- Name all the colors he sees in the house.
- Tell the names of furniture and the room where it belongs.
- Sort objects according to size, color, shape, texture onto paper plates.
- "Read" a book to you. Describe book by looking at pictures. Ask him/her questions about it.

Follow this link to our website (tools tab) for the entire list under each domain describing what to do to support your little one!

http://www.kaleidahealth.org/childrens/services/display.asp?pt=G&p=1266&s=681