Resources on Access, Support, and Advocacy in the Health and Insurance Worlds

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The Advocacy ATLAS

Accessible Tools for Leadership and Advocacy Success
The Advocacy ATLAS

www.geneticalliance.org/advocacy-atlas
Using Our Voices

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Advocating for Your Family

- Navigating and Maximizing Private Insurance
- Eligibility for Public Programs
- Braided and Blended
- Not Extra -- Essential
  - Understanding Coverage
  - Understanding and Using Appeals Process
  - Relationship-based Advocacy
Advocating for Your Family

- Writing Winning Insurance Appeal Letters - The Oley Foundation
- A Lifetime of Advocacy: What Families and Individuals with Turner Syndrome Need to Know
- A Greater Understanding -- Patients: How to Discuss the Costs of Healthcare Treatments With Your Provider - Patient Advocate Foundation
Advocating Local/State Level

- Changes to Your Insurance Policy
- Providers Accepting Payment
- State Level Policy
- Funding
- Public Knowledge
- Accessibility
Advocating Local/State Level

Advocacy Tip Sheet- Kids as Self Advocates (KASA)
Advocating at National Level

• Philosophy
• Policy
• Funding
• Programs
Advocating at National Level

• How to Use the Media in Your Advocacy Efforts-Video- Immune Deficiency Foundation

• Health Care Equity Tool Kit for a Winning Policy Strategy- The Praxis Project
Ways to Communicate About Your Health

by-
Kim Norris-Scrano
Busy Mom and Family Advocate with PLUK Parent Center at The Children’s Clinic in Billings, Montana
Alana’s Story

• Alana was born with a chromosomal difference, Tetrasomy 9p
• Aspects of Alana’s uniqueness have been visible since birth
• People have not always known how to react to her
• So, I have 12 years of experience explaining the amazing kid that she is!
• One way I help explain her is by reading “Alana’s Story”
Hi, my name is Alana, and I am 7 years old.

My birthday is March 30th. I like to wear a crown and eat ice cream on my birthday!

What do you like to do on your birthday?

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Sometimes kids and grown-ups have questions about me.

Some people call me a baby because I am small. I don’t like it when they say that.

Some people ask why I have a hole in my neck.

I am a big girl. I have lost 5 teeth!

Do you see where my tooth is missing? Do you have any teeth missing?
When I was a baby a doctor put a tube in my throat. The tube helped me breathe. The hole in my neck is from the old tube.

Has a doctor ever helped you?

Some people wonder why my nose looks different.

When I was a baby I had a cleft lip. I couldn’t blow my nose or eat. I had an operation. Now I can eat my favorite food, yogurt!

What is your favorite food?
When I eat I use a big squirter. Sometimes people have questions about that too! I use a big squirter because it is easier than using a spoon!

Sometimes I pretend to feed my doll with my big squirter. What do you pretend to do?

Some people wonder what I am saying when I use my hands to talk.

I know a lot of words in sign language, but I am not deaf. I can hear what you are saying too!

Would you like to learn how to talk with your hands? I can teach you!
I make a lot of sounds with my mouth too. Sometimes people have a hard time telling if I am making sounds that are happy or sad.

One of my happy sounds is a loud scream that sounds like, “Ahhh, Ahhh, Ahhhhh!” I usually make this sound when I wash my hands. I love to wash my hands!

What do you love to do?

I cough a lot and my face turns red. I cough when I cry and I cough when I wake-up.

People always have questions about my coughing. I am OK. I am not sick, but you can rub my back if you want to.
You can do other nice things, too! Sometimes I don’t realize when I have saliva on my chin.

If this happens, then you can get me a tissue and remind me to wipe my chin!

What do your friends help remind you to do?

Some people wonder what I like to do with my friends. Well, I do love to play dress-up, but I also like to play basketball!
I also like other sports like bowling, gymnastics, and even skiing!

Of course I can’t always play! I go to school, too! Some people wonder what I do in my classroom.

Well, it is a lot of fun! I work on my letters, numbers, colors, and shapes! I have art, music, library, and P.E. I also get to cook in my classroom, and we take a lot of field trips!

What is your favorite sport?

What are some of your favorite things to do at school?
Sometimes people don’t know what to think of me when they first meet me!

I am different from other kids, but different is good! And, I am a great friend once you get to know me!

What makes you different?

This book answers a lot of questions! Questions are good. Everybody learns by asking questions!

If you have more questions about me, then please ask my mom or my teacher!
Communication, Communication, Communication

• This story was written for children, but it has been used with Alana’s grandmas, grandpas, aunts, uncles, teachers, therapists, family support specialists, childcare providers...

• Sometimes adults need as much-or more-help understanding her individuality!

• The story has also been used with Alana’s cousins, classmates, and children in her after school programs

• It always helps start necessary conversation that leads to Alana being better understood, accepted, respected, and included!
Communicating About Your Health

- [www.geneticalliance.org/advocacy-atlas/communicating-about-your-health](http://www.geneticalliance.org/advocacy-atlas/communicating-about-your-health)

Alana’s Story can be found on this site, the idea is families can use this as a template or inspiration for their own stories.
Other Resources

- **In Our Own Words: Using Family Stories to Teach Family Centered Care** - Parent to Parent of Vermont
- **Partnering with Your Doctor: The Medical Home Approach** - Region 4 Genetics Collaborative
- **Talking With Your Doctor and Other Health Care Professionals Video** - Institute for Child Health Policy at the University of Florida
Other Resources, Cont.

- You Are an Advocate for Your Child with Special Health Care Needs - Family Voices
- Self-Advocacy For All: Stories from Self Advocates - Research and Training Center on Community Living at The University of Minnesota (Importance of Sharing Your Story)
Lessons Learned So Far

• Every question is an opportunity to advocate
• I seldom give the same answer to similar questions
• People ask questions for different reasons
• So, before answering a question, I inquire, “Just curious, why do you ask?”
• I teach others how to feel about Alana
• If I am OK with her, then they are OK, too!
• I am always amazed at the things people don’t know about Alana, especially when they have known her for YEARS!

• Don’t assume people know what you THINK they know
• There is almost always opportunity for additional awareness!
• **Vision:** All children with disabilities and special health care needs grow up in a family who supports them to lead full and happy lives in their communities.

• **Mission:** P2PUSA promotes excellence in P2P programs across the nation. There is hope, strength, and power in connecting parents of children with disabilities or special health care needs.

• **We believe...**
  • that every parent’s journey has value.
  • in the strength and resiliency of parents.
  • in the power of parents supporting one another.
  • that support should be available to parents and families throughout the lifespan.
Parent to Parent Basics

• Parent to parent support, promoted by Parent to Parent USA, is the intentional matching of an experienced, prepared, Support Parent with a parent seeking peer support.

• Parent to Parent USA Alliance Members are statewide organizations providing support and information to families with children who have special health care needs or disabilities, most notably through parent to parent support.
Connect or Collaborate with an Existing P2P Alliance Member

1. Go to www.p2pusa.org
2. Click on “Looking for Support”
3. On the US map, click on your state for all contact information

Or...contact Kathy Brill at (717) 503-8992 or ksbrill@p2pusa.org to further discuss your needs and plans
Family Voices

- **We are** . . . a national family-run non-profit organization founded (1992) by families of CYSHCN to activate family roles in health care

- **Our mission is** . . . to achieve family-centered care for all children and youth with special health care needs and/or disabilities
Family Voices

➢ Through our work, we . . .

• Provide families with **tools to make informed decisions**

• Encourage **self advocacy/empowerment in youth/young people** with disabilities

• **Build partnerships** among families and professionals

• **Advocate** for improved public and private policies

• Serve as a **trusted resource on health care**

www.familyvoices.org    www.fv-ncfpp.org
FV-NCFPP is the **National Center** dedicated to the MCHB outcome measure: *families will partner in healthcare decision-making for CYSHCN at all levels*. We

- Created the concept of F2F HICs and pushed for their funding
- Provide peer mentoring, support, training, TA to family leaders in every state
- Promote partnerships between families and professionals by providing tools, opportunities, and mentorship

[www.fv-ncfpp.org](http://www.fv-ncfpp.org)  [www.fvkasa.org](http://www.fvkasa.org)  [www.familyvoices.org](http://www.familyvoices.org)
Empowering Families

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- Kathy Brill, ksbrill@p2pusa.org
- www.familyvoices.org
- www.fv-ncfpp.org
- www.fvkasa.org
- www.fv-impact.org
- Bev Baker, bbaker@familyvoices.org
View The Series!

• **Webinar 1 (9/23):** Empowering Individuals and Families as Advocates

• **Webinar 2 (10/15):** Resources for Advocacy Through the Transition Years and Beyond

Recordings available on Genetic Alliance YouTube Channel
Thank You!

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