



Passing on Your Left: My 2014 Ironman Journey

CHRIS ANDERSON



For many people who stutter there exists a belief that they cannot do certain things, as they are often told that stuttering will get in the way of their lifelong dreams. I am no exception.

Over the past few years, I hit a bit of a rough patch in my life and felt like I was not doing or accomplishing the things that I had always wanted to. My judgments were becoming severely impacted by a low self-confidence because of my stuttering struggles. I believed that I just had to continue taking all the lumps and be hardened to the fact that eventually all the perseverance would pay off.

A little over a year ago, I said enough was enough and decided that the only way out would be to challenge myself and begin the road towards acceptance as a person who stutters. Heading down this new road, I started crossing the things off of my list that I had always wanted to do, but had always thought impossible because stuttering would somehow hold me back.

First on the list: become an Ironman triathlete, which involves swimming 2.4 miles, biking 112 miles, and running 26.2 miles for a total of 140.6 miles, *all in one day*. One big problem – I didn't know how to swim, nor had I ever run a marathon, much less completed an entire triathlon. Still, I was determined to challenge myself. I saw that the confidence that I was gaining through my commitment to the training was spreading to other aspects of my life. For example,

as I taught myself how to swim, I decided to start speech therapy again after a break of more than seven years. As I was tracking my training, I was paralleling my daily therapy assignments with my daily work-outs to stay accountable.

Six months after I began training I completed my first Half Ironman race (70.3 miles) and participated in two workshops at the NSA Annual Conference in Scottsdale, Arizona (which just happened to be another lifelong goal!). Both of these endeavors were life changing for me, as I had never imagined that I would be able to complete them prior to my newfound effort to take my life back.

However, I am not done yet! I am registered for the Lake Placid Ironman in July 2014, which will be my first full Ironman race. Working towards this goal has been and will continue to be a huge boost in self-confidence, which has also led to many successes in my speech therapy as well as my acceptance of myself as a person who stutters.

Participating in this race brings an opportunity to fundraise, which I am choosing to do on behalf of the NSA. My hope is to raise enough money to allow other people who stutter to attend a conference when they may not otherwise be able.

"Passing On Your Left" is an effort to raise money for those who stutter, those who have been lucky enough to have their lives impacted by stuttering, and to inspire change or acceptance in everyday life. 

Conference Update

We know that preparing for and attending our conferences means a lot of forms, paperwork, and information. Here are a few tips, tricks, and items to check off of your to-do list to make your conference experience as fun, simple, and productive as possible.

- **Room reservations** at the Renaissance Downtown Washington, DC Hotel are now OPEN! Book your hotel reservations as soon as possible because this property WILL sell out quickly. Once again, the NSA will be able to offer you a generously discounted room rate.
- **Conference registration** is slated to open on/around January 15th. Be sure to send in your Registration Form by mail/fax/email or register online by Thursday June 19, 2014. After June 19th, you may only register on site.
- This year we are working hard to put together a **Conference Program** schedule that kids, tweens, teens, families, adults, and SLPs are sure to enjoy. Applications for workshops are now being accepted, but be sure to get your applications in by March 1, 2014!

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Be sure to check out 'WeStutter' on Facebook and Twitter today!

www.WeStutter.org

CHAPTER NEWS

DAVID BLAZINA

Twin Cities, MN

Linda R. Hinderscheit reported that the recent meeting of the Twin Cities chapter of the NSA had 11 people in attendance including six PWS, including one newcomer! The five attendees who did not stutter included four SLP grad students from the U of M and one parent. Our new chapter attendee contributed a great deal to the meeting and the group was thrilled that he came! It was a fairly informal meeting as everyone focused on catching up with one another and events that had happened over the summer. The group also discussed some possible options for topics to discuss at upcoming meetings.

At the December meeting the group plans to have a “book club” meeting, where discussion will focus on the recently-released book by **Katherine Preston**, *Out With It: How Stuttering Helped Me Find My Voice*. Everyone agrees that it is a very well-written book which accurately describes the internal and external experiences of a person who stutters, and the group would like to discuss it in further detail.

The group also continued their discussion of the use of mindfulness practices in the management of stuttering, and will have the chance to experience some of the practices (for example, the body scan) at the next meeting. Participants will also revisit the topic of listening and apply mindfulness practice to listening to another person.

Other future meeting topics contributed by members include:

- Voluntary stuttering (November meeting)
- Use of the phone
- Acceptance (not beating ourselves up)
- Difficulties in group communications, including the awkwardness of not feeling part of the group and the difficulty of physically initiating speech

4th Annual “Take Stuttering to the Ballgame” Event

Mitch Trichon, Queens chapter co-leader, reported that the 4th Annual Mets Outing for the National Stuttering Association was a great success. “Great food, great weather, and a win, but most of all, great people!” Special thanks goes out to all of those individuals who helped to organize the event, including **Nina Z.** and **John D.** – the Queens chapter co-leaders.

Chicago Metro North Chapter

Art Struss reported that the Chicago Metro North chapter enjoyed an outing to the Morton Arboretum, and a great time was had by all. The weather was great, the group reaffirmed that the Morton Arboretum does, in fact, have hills, everyone enjoyed having the chance to touch base at lunch with those in attendance. The group also wishes a very happy birthday to **Luba** and **Anthony!**

Cincinnati, OH

Tom Scharstein noted that the Cincinnati South Chapter is beginning their 4th year, and continues to fuel their involvement and involvement.

Recently the chapter has discussed positioning themselves for a circle topic as a clock face, and referred to this “clocking in.” After an explanation at a recent meeting, one of the groups newer participants positioned herself at 1:00 for the topic of “100% Fluency”. Since many are new to the realization of a strategic position during business or school in the dreaded anticipation of going around the room to introduce oneself, “Clocking In” proved to be a topic in itself, due to its relevant nature.

“100% Fluency” concerns a location, circumstance, or safe place beyond the influences or performing pressures from others. Thus the question, “Is there or has there been a place in your life where you are/have been totally fluent, such as your room, your car, your office?” One chapter participant posed this question, which then transformed into an informal survey, and found that in 208 responses, only one PWS admitted to not having a “sphere of safety” in which they achieved fluency.

Austin, TX

Chapter co-leader **Ryan McDermott** reported that there were eighteen inspirational and supporting people in attendance at their recent meeting. Included were eight persons who stutter, four SLPs, four parents, one student SLP, and one girlfriend. Out of this group there were eight first timers. The chapter welcomes **Michael** (PWS), **Zoi** (SLP), **Racquel** (girlfriend), **Adriana** and **Sam** (parents), and **Tanner** along with his parents **Cyndi** and **Glenn**.



The meeting started with a reading of the welcoming words by Michael. Even though this was his first meeting, he had absolutely no problem with immediately stepping up! Afterwards the group moved into announcements, including a discussion of the Open House, to be held November 4. Last year, the chapter hosted approximately 80 people, and they are hoping for an even bigger turnout this year. During announcements the group also discussed the NSA Annual Conference in D.C. in 2014 as well as their chapter fundraiser. So far they have raised \$450 towards their goal of \$2,000!

After announcements participants moved into the topic for the night, facilitated by **Hayden Lambert**. His topic was, “Fear and How to Overcome It.” Hayden opened up the discussion by reading a few passages relating to fear from Katherine Preston’s book, *Out With It: How Stuttering Helped Me Find My Voice*. Hayden made the point that no matter how far you think you’ve come, it’s a constant push to control our fears as a result of our stuttering. Afterwards participants split up into groups for about twenty minutes to discuss the topic of fear and how to overcome it. Three questions were given to the groups to discuss: 1) Have you overcome or almost overcome fear about stuttering? 2) Do you have fears about this upcoming year? 3) How do you approach a specific situation?, followed by summaries of what each group discussed.

One group discussed how sometimes avoidance is out of convenience and not necessarily fear. However, when avoidance becomes a result of fear, it is best to try and confront the avoidance before it becomes habitual. Nevertheless, participants also agreed that one possible cause of fear towards stuttering could be the desire to avoid shame. Another group discussed similar ideas to the first including the difficulties of overcoming fear in specific social situations. The last group shared that one way to avoid anxiety before

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A Message from our Board of Directors Chair

SHERYL HUNTER



Hello friends! While I only know a small fraction of you personally, I feel a connection to every member of the stuttering community. Every single person involved in the

NSA becomes a part of fulfilling its mission to be the voice of those affected by stuttering. You all have something to teach, to share, and to contribute to this community. Most of all, remember that just by telling someone about the NSA – a parent, a teacher, a physician, an employer, your Facebook friends - you can change lives.

In this, my second year as Chair and fifth year on the Board of Directors, we made great strides toward taking the NSA to another level. The seeds, roots, and trunk of this organization are made from the nutrient rich nature of self-help. People helping people through mutual support and sharing of information underlies all that we do. Self-help is what has inspired and nourished our Annual Conferences, our localized events like Family Fun Days, our educational materials,

and our chapters throughout the country where hearts and minds deeply connect.

It is exciting that the seeds of the NSA, planted thirty-six years ago, are no longer just roots and a sturdy trunk. We now have a lush, maturing tree with multiple branches that are growing and bearing fruit.

We have a research branch, providing a highly regarded research symposium where experts gather to share what they know and what they have yet to discover and to foster coordination of these efforts. We also offer grants that bring recognition and funding to those seeking answers to our questions.

We have a professional support branch, offering information and continuing education to speech language pathologists at our clinical symposium and throughout the year. There are clinicians who strive to be the best they can be for people who stutter and their families, and we are able to help them help us.

We also have an education and advocacy branch that includes our online and print materials and calls to action to educate the broader public about stuttering and the rights and dignity of people who stutter.

Each of these branches can reach further, cover more ground, and produce more seeds for extended impact. The Board of Directors and the new Advisory Board have been working hard to position the NSA for the healthy growth of all of these important elements of the life of the NSA. Outreach and support, education and advocacy, research and professional support are so deeply connected that they thrive when brought together into one living organism rooted in self-help.

As you look back on 2013, consider all of the ways in which the NSA has touched your life and how you can contribute to its healthy growth in the years to come. If you have ever read Shel Silverstein's famous children's book *The Giving Tree*, the story of a boy who took from the tree throughout his life, the tree seemingly happy to keep giving, you know that eventually the tree has no more fruit, shade, or even wood if it is depleted and not nourished. This holiday, think about making a gift to the NSA or volunteering your time and talents so that we can flourish and serve for generations. Every dollar bears fruit. 🌱

CHAPTER NEWS *continued*

a feared event is to focus your attention on other things that you are able to control. For example, accepting your stutter can help you eliminate some of that anxiety associated with it.

The group ended the meeting with closing words read by **Jonathon McNutt**.

Muskingum Valley/SE Ohio

KC Frick reported presenting at Ohio University in Athens to a group called "Creative Expressions", comprised of undergraduate SLP students considering SLP graduate school. The group serves local schools for communication disorders.

33 people (all females) attended the presentation, and KC was able to speak for 40 minutes and cover the NSA web site and brochures/NSA information supplied by the Nation Office. Most of the students were not familiar with NSA, nor had they much training with stuttering.

KC was also able to promote the Zanesville NSA Chapter, approximately 60 miles away, and to solicit help, which resulted in two students wanting more information and to volunteer their services.

San Diego, CA

Alex reported that there were four speech language pathology students from CSU San Marcos and six NSA members present at the recent meeting. After introductions and an icebreaker with the topic of "talk about something nice you have seen someone do for someone else", the group discussed William Perry's Valsalva maneuver book that one of the chapter members is currently reading. The speech students had several questions for the group, such as what we thought about therapy and what it feels like to stutter.

The chapter also recently designed a flyer (*right*) that they have been posting around town and dropping off in therapy offices.

RIGHT NOW...

THERE IS A MOM LOSING SLEEP
BECAUSE HER 3-YEAR OLD DAUGHTER IS STARTING TO STUTTER & SHE DOESN'T KNOW WHAT TO DO

THERE IS A 30-YEAR OLD MAN REALIZING HE DIDN'T PURSUE HIS DREAM CAREER
BECAUSE HE FEARED HIS SPEECH WOULD GET IN THE WAY

THERE IS A YOUNG BOY STARTING 5TH GRADE WALKING TO SCHOOL INSTEAD OF TAKING THE BUS BECAUSE HE HAS BEEN BULLIED ABOUT HIS STUTTER

THERE IS A TEEN WONDERING
IF ANYONE ELSE IN THE WORLD COULD POSSIBLY UNDERSTAND HOW HE FEELS

THERE IS A 20-YEAR OLD WOMAN SITTING AT HOME ALONE
BECAUSE SHE WAS TOO AFRAID TO ASK SOMEONE TO THE PARTY

THERE IS A DAD FEELING GUILTY
BECAUSE HE CANNOT MAKE HIS SON'S STUTTERING SIMPLY 'GO AWAY'

THERE IS A LITTLE GIRL IN 2ND GRADE MAKING UP AN EXCUSE
TO MISS SCHOOL BECAUSE SHE KNOWS IT IS HER TURN TO PRESENT IN FRONT OF THE CLASS

THERE ARE SO MANY PEOPLE WHO STUTTER WANTING TO GIVE BACK TO THE STUTTERING COMMUNITY BY SHARING THEIR SUCCESS STORIES

THEY NEED THE NSA & THE NSA NEEDS YOU - PLEASE DONATE TODAY

Congratulations to **Landon Murray** and **Lizzy Mayer** on their recent wedding! Landon and Lizzy were wed on Saturday, October 5 in New Orleans, LA. Best wishes to both of you for a long and happy life together!

The NSA wishes to congratulate **Cathy Olish Maciejewski** and husband Ron on the recent birth of their beautiful first child, a son, Luke. Congratulations to the happy parents!

Tempe, AZ CEU – another outstanding turnout! Approximately 50 area SLPs were treated to another outstanding CEU workshop sponsored by the Metro Phoenix



NSAKids and TWST Chapter. The program was presented in conjunction with the annual Family Fun Day on October 26, 2013. **Vivian Sisskin**, an ASHA Fellow and a

clinical faculty member at the University of Maryland, presented a multidimensional framework for assessing observable speech dysfluency and the related psychological and social aspects of stuttering. Among her many contributions to the field, Vivian is a former member of the Board of Directors for NSA. She has a long record of service to persons who stutter and to the SLPs who serve them. In addition to using traditional integrated therapies, Vivian has made notable contributions toward the understanding and practice of Avoidance Reduction Therapy. Participant responses were overwhelmingly positive for the event.

The National Stuttering Association was pleased to be back in Boston at **Boston University/Sargent College** on November 2, 2013 to offer a Continuing Education Event (in conjunction with a Family Fun Day) to speech & language professionals. We hosted more than 60 speech-language professionals from the greater Boston area attended the presentation by **Lisa Scott, PhD, CCC-SLP**, Director of Clinical Education at Florida State University, addressing 'Practical Strategies for Speech Modification Instruction'. The event was enjoyed and well-received by all who attended.



Putting Hope into Practice

D. RACHEL MCCULLOUGH, PH.D.



In the Fall of 2012, my agency at the U.S. Department of Justice planned a series of events to commemorate National Disability Employment Awareness Month. It was through this initiative that I had the opportunity to suggest a workshop on stuttering. I figured it could both shed light on what stuttering is and is not, and in the process I would be forced to do some "advertising," a goal that I had been working on with my speech language pathologist. And then, in typical fashion my thoughts changed to, "Wait... what was I thinking!? Do I *really* want to go through with this? Give a *presentation*? On stuttering? At work!?" It was that push-pull of "here is an opportunity to advertise, enlighten, and be of service to others" coupled with being scared out of my mind.

This was a turning point for me, and not a small one at that. You see, I've stuttered since I was six years old and for most of my life, I've tried to hide it. It often worked. It often didn't. If I were to put on this workshop, there would be no more hiding – ever; no turning back. I had a choice to make.

My mind flooded with memories about stuttering. There is too little space in this article to describe the impact stuttering has had on my life, but if you stutter or if you are close to someone who stutters, then you already know that it affects almost everything! Growing up stuttering, I reluctantly kept to myself when I really wanted to join in, I shrank when I wanted to stand out, and I kept quiet even when I had something to say. I became really good at using synonyms and switching words around, using starter words, and my all-time favorite, "dumbing myself down" and pretending like I had simply forgotten what was I going to say.

As a kid I trained myself to be painfully invisible, lest someone ask me a question and force my stuttering secret to spew out into the atmosphere. Lest

someone look at me with impatience when I repeated a sound or made a running start for that 'W' word, only to start the sentence over and try again. Lest someone give me that horrified look that says, "What is happening to you?"

But years of hiding stuttering can wear out a soul, and by my thirties it was wearing out mine. My husband noticed it too. It was – in a word – exhausting. I sought help, and in doing so realized that, aside from the physical mechanics of stuttering, my trouble was that *I did not want to accept that I stuttered*. Throughout grade school, college, and graduate school, I just wished it would go away. I wanted to speak normally like everybody else. Working with my SLP was helpful, but only to a point. How can you use speech strategies when you're worried that using them will make it sound like you're a stutterer using strategies? It can drive you batty.

Over the years I tried many ways to accept my stuttering - journaling, meditation, and the like, but I felt like I needed to see how PWS who *didn't* have shame about their stuttering, stuttered.

I needed to hear stuttering. Lots of it.

I needed to feel free to stutter. All of the time.

It was then that I packed my bags, kissed my husband goodbye, and put myself on a plane headed to the NSA Annual Conference in Fort Worth, Texas. There I was, smack-dab in the middle of more than 900 other persons who stuttered.

One night I met NSA Member and workshop moderator, Cathy Olish. Within 5 minutes of us meeting, Cathy looked at me and said, "You're a Covert Stutterer, aren't you?" I didn't know what she meant. Soon I was gasping in disbelief as I sat in at the workshop "Covert Stuttering Exposed!" and one by one, heard the speakers tell my story. The PowerPoint presentation explained that covert stuttering was a "Subgroup of PWS who attempt to maintain the facade of fluency at ALL COSTS." Then, that LIST showed up on the screen:

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PUTTING HOPE INTO PRACTICE *continued*

- Having excessive fear of being perceived by others as being different because of stuttering?
Check.
- Fear of the “secret of stuttering” being discovered?
Check again.
- Guilt for making the listener feel uncomfortable because of the stuttering?
Ugh, I hate that. And, oh yeah, check!
- Denial of the stuttering or the need to work on it?
I'd like to think I was being an optimist, but ok, check!
- Shame, the devaluation of oneself, festers the need to hide stuttering?
Sigh, one big fat CHECK!

It was at this workshop that I learned that there was a word for my type of stuttering. It was called *covert stuttering*, and I wasn't alone. I saw intelligent, beautiful, funny, and strong people who stuttered without shame. Everyone's stutter was unique, pure, and gorgeous; like a snowflake. My perspective was shifting. By watching them, I learned that I didn't have to be ashamed of my stuttering either, and I returned home full of hope.

By 2012, I was given the chance to put that hope into practice. One of the many reasons I had previously hidden my stuttering was the fear that people would label me and would assume things about me that were not true, like I was nervous or unintelligent. When I had the chance to create an educational event about stuttering, I knew that myths were going to be part of the agenda.

I felt like I was running into a fire. If people didn't know that I stuttered before, they knew now! As a covert stuturer, the last thing in the world that I would have ever wanted to do is to tell people that I stuttered, let alone give a workshop about stuttering. However, that's exactly what was happening.

On November 8, 2012, we held the workshop, and people showed up! My supervisor, my supervisor's supervisor, the chief of staff, and senior management and coworkers from across the divisions, all showed up. There had to be more than 50 people coming to learn about stuttering - on their lunch hour no less! The next hour was nothing short of transformative.

It is important for me to tell you that this all happened slowly, over many years, with lots of starts and stops and lots of support. It is also important for me to tell you that I had to find my own path and what works for me. What I see in other NSA members who are truly comfortable in their skin seem, is that they seem to have found out what works for them. What works for them might not work for me, and what works for me may not work for you, and that's all cool, because we're each finding out what works for us. 🐾

CONFERENCE UPDATE *continued*

- Are you a **First-Timer** who is on the fence about attending? Rest assured that the four days that you spend at our Annual Conference will change your life...for the better! Ask anyone who has attended in the past about their conference experience, and you can expect to hear stories of realizations, facing fears, good times, tears, triumphs, and the formation of lifelong friendships.
- Thanks to the generosity of corporate sponsors and many of our members, we are pleased to offer financial assistance through the **NSA Annual Conference Scholarships** for people who stutter who would like to attend our Annual Conference. We feel strongly that our conferences should be open to all, regardless of finances. However, we ask that you also check into other resources prior to applying to NSA for financial aid funds, as *we do not provide 100% scholarships* for anyone.

For more information on these items and much more, visit WeStutter.org, and we will see you in DC! 🐾

