

...for kids and teens who stutter, their parents, SLPs and others who support them!

family Voices



National Stuttering Association

Changing the lives of people who stutter

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Strengthening Our Core

By Sheryl Hunter

We have two wonderful children, Logan (6) and Aspen (4). When asked by friends without children "what is the hardest thing about being a parent?" my answer is always the same and can be summed up in one word: vulnerability. The love for a child is so deep and so raw that there is always a sense of tremendous vulnerability that any injury to their mind or body will be extraordinarily painful for mom and dad. It is this vulnerability that makes those amber alerts and pediatric cancer headlines unimaginable and heartbreaking.

We are thankful that our son's stuttering is the only serious challenge we have had to face, but it has enhanced that vulnerable feeling. Those of you reading this article know too well what I mean by



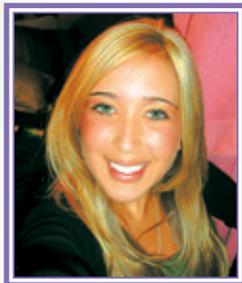
this. We feel it when I drop Logan off on the first day of a new camp. When he is asked his name. As he begins to tell a story that he may struggle to finish. These fears are justified by realities he faces every day.

As I witness Logan's confidence in the face of stuttering I am convinced of the importance of his father and I being confident in his strength. It is our job to empower our family to fight off the sense of vulnerability that comes from a speech disorder. We have to educate Logan that there are many ways to express oneself in this world

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Join the TAC...

By Stephanie Nicolai



Being on the teen advisory council may be a lot of work, but it definitely has its benefits and it's shown me a completely different side of the NSA and my outlook on my stuttering. Being at the conference is by far the busiest time for us. If you've been to a conference, you have probably noticed at least one of us at each kid workshop and running around like crazies. The family programs leaders like to keep us busy by either making sure we are at some type of workshop, showing families

around, interacting with the kids, or even getting a coffee and pastry for the booth workers. It gets a little exhausting after a while, but it gives you the opportunity to talk to everyone in the NSA and not just the teen group.

A very important part of being a TAC member is interacting with the kids of the NSA. When I came to my first conference when I was 11, I remember looking up to the teens as role models and hoping I could be as confident and cool as they were when I got older. Now that I'm 19, I keep those memories in mind when choosing whether I should hang out with my age group or go skip up and down the halls with the kids. I usually go with the kids, especially considering I'm one big kid myself. I try to meet as many kids and develop as many bonds as I can, because I remember wanting to really get to know

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The 2009 NSA Annual Conference Scottsdale, Arizona

The annual NSA Conference is the premier meeting of people who stutter, including children, teens, parents, and professionals. Everybody gains insight from professionals and most importantly, from each other.

Parents who have experienced the NSA conference have said they wish they had known about us years before. This is a rare chance to meet face to face with other parents of children who stutter, adults who stutter and some of the most outstanding stuttering specialists in the world. Come, listen, learn, ask questions and share stories with others! Parents are encouraged to bring children who stutter (ages 7 and older).

We are excited to bring you three days of activities during the conference beginning at 8:30 am on Thursday. The **Family Orientation Workshop** will familiarize you with the conference schedule while giving you a chance to become acquainted with the Family Programs staff, the **Teen Advisory Council** and other families. This three-day program will provide you with the opportunity to network with leading experts who specialize in working with children and adolescents who stutter, as well as with other families. Your questions will be answered and parents will meet other parents while their children explore their stuttering in a fun and safe environment. Other activities include pool parties, parent and youth round table discussions, a scavenger hunt for the kids, and much more! *These are three days you don't want to miss!* ■



Any questions? Contact: Debbie Nicolai, Family Programs NSA Board of Directors, DEBNICO@aol.com

Ask the Expert:

by John Tetnowski, PH.D., CCC-SLP

During the 2008 NSA National conference, I was part of a discussion group labeled as Stuttering 101. Many different questions came up, and I would like to share some of the discussion with parents and their children regarding several different major points of discussion.



Here are some of the big ones!

Q. I have heard that there is still no cure for stuttering.....has anything really changed in terms of therapy for children and teens over the past few years?

A. There have been quite a few advancements in the treatment of stuttering over the past several years. Included in these advances are improvements in treatment outcome measures (how well someone does in therapy), advancements in the pharmacological treatment of stuttering, advances in microelectronics that have had an impact on the use of devices for the treatment of stuttering, and improvements in imaging techniques that have allowed us to examine what is happening in the brain when stuttering occurs.

In spite of these advances, the two types of basic therapy remain the same. That is, one type of treatment seeks to eliminate the stuttering (fluency shaping), while the other attempts to lessen the effects of stuttering on the individual (Stuttering modification). Plain and simple, the goal of fluency shaping is to eliminate or greatly reduce stuttering. Within this area, successful treatment outcomes provided by behavioral techniques employed by parents (such as the Lidcombe Program) are very promising. The Lidcombe Program developed by Mark Onslow and his colleagues in Australia, has documented a very high percentage of success in young children who are developing stuttering. These children have been successfully treated without any long-term side effects. It is impressive to note that these children have maintained these levels of fluency over the long term. Keep in mind that these programs have been developed for young children and do not have the same levels of effectiveness on older children and adults.

Somewhat related, are the epidemiological studies conducted by Dr. Ehud Yairi and his colleagues at

the University of Illinois. They have shown that many children do recover from stuttering (even severe stuttering!) throughout their childhood years. In the course of their studies, they found that recovery can occur as long as four or five years beyond when stuttering had its onset. An important contribution from their work included the term "stuttering-like disfluencies". The term "stuttering-like disfluencies" has been used by this research team to label speech behaviors that are the most indicative of stuttering. These include part-word repetitions, prolongations, and blocks. The data from these studies can be used as active predictors as to whether stuttering will continue to develop or whether recovery is likely. A knowledgeable and skilled speech-language pathologist who treats stuttering should be well versed in the work of both of these research teams.

Unfortunately, there is some debate between these two groups of researchers as to whether the impressive results of the Lidcombe Program are due to the effects of intervention, or are skewed by the early recovery data obtained from the University of Illinois studies. Once again, a knowledgeable and skilled clinician can help you interpret this important data. As a starting point, skilled clinicians in your area can be sought out through the Specialty Board in Fluency Disorders. Information on speech-language pathologists holding specialist credentials in fluency disorders can be obtained at the web site www.stutteringspecialists.org.

In summary, these two groups of researchers have carefully added a great deal of information to our current knowledge base of stuttering. The future will weave these two theories together to give us a better picture of the course of early stuttering.

In the next several issues, I will be reviewing our discussions and answering questions on important issues related to stuttering modification, the use of fluency enhancing devices, pharmacological treatments, brain imaging studies, and anything else that you may be interested in discussing. If you have any questions in addition to those we discussed at the 2008 conference, feel free to send me a message at tetnowski@louisiana.edu

John Tetnowski, Ph.D., CCC-SLP is the Ben Blanco Endowed professor of Communicative Disorders at the University of Louisiana at Lafayette. He is a Board Recognized Fluency Specialist and Mentor. He is the Coordinator of the Ph.D. and M.S. programs in Speech-Language Pathology at the University of Louisiana at Lafayette. He is on the NSA's Board of Directors, where he heads both the Professional Relations and the Research Committees. ■

Bound and Determined

by Joseph C.

My name is Joseph. I'm 15, live in Colorado Springs and am a person who stutters. My life goals are to go to the Air Force Academy, become an aerospace engineer, and then a pilot. But to reach these goals and control my stuttering is why I go to speech therapy classes. When I first walked into speech therapy classes, she told me a lot of useful things, things such as light and long first sound, not to use avoidances, word classes, and how to voluntarily stutter. I had no clue what those terms were initially, until my speech clinician thoroughly explained what they mean. Always remember, the therapy classes seem hard at first, but with practice and continued speech therapy, fluent speech becomes easier to incorporate into your daily life. This is why I find that they help out a lot.

One reason that they help out is that they boost your confidence levels tremendously. I used to hate talking in front of classes and with other people. I was afraid that I would start stuttering and they would make fun of me. The reason speech therapy helped out with confidence is that they make you feel more calm so that you can focus on the techniques you have learned in your classes.

Another reason that I find the classes help is that you can speak and be understood the first time you say something. When you stutter people are always asking you to repeat things and that can get very annoying. After the class you can speak more clearly and people understand you more, and you can get a better answer out of them.

Lastly, speech therapy class helps because it helps you understand what it means to stutter. When people ask you the question, "What is stuttering?" you can give them a clear definite answer, instead of making things up. If someone used to come up to me I would just make something up on the spot, I can say that our voices turn on slower.

Submitted by: Mary Elizabeth " Libby " Oyler , Ph.D. , CCC-SLP, CBT
NSA Chapter Leader- Colorado Springs , Colorado 80918 ■



My Friends Make Me Feel Good About Stuttering

by Roseanna G.

Hi, my name is Roseanna G , and I am from Brooklyn , NY . I go to St. Edmunds Elementary school and I am in the 8th Grade. A couple of weeks ago I brought my two best friends into speech class and gave a presentation about stuttering. When they first got there, they were a little nervous, but once they found out what stuttering was, they were cool about it. It helped me to have my friends come in, because it gave me more confidence to speak in class. They liked it so much that they wanted to come back. I liked it too. It doesn't matter if I stutter when I'm talking to them because they won't make fun of me or finish my words. I'm glad I brought them in. (see attached photo-Roseanna is the one on the right.)

A couple of months ago, I ran for secretary. I had to make a speech in front of the whole school (which is nursery-8th grade). I'm glad I did it because at first I was nervous, but when I got up there to read, I was fine. The next day we found out who won. I didn't win, but I was glad I did it anyway!

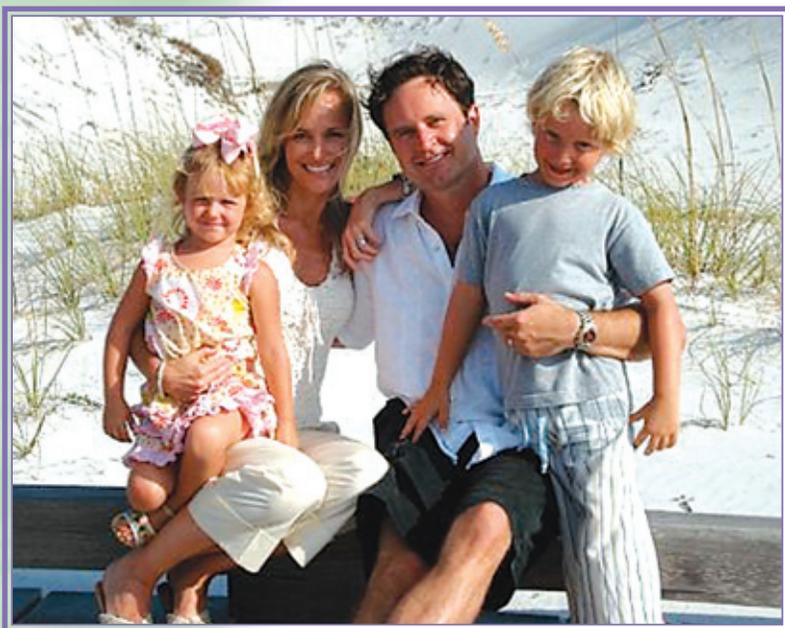
Submitted by: Rozie Matthes, M.S., CCC-SLP, BRS-FD ■



Strengthening Our Core: cont from page 1...

and he does not have to have perfectly fluent speech to live a full and meaningful life. The beauty of life is that it is filled with limitless means to achieve happiness and success: art, academics, music, adventure, sports, friendships, travel, work, volunteerism, family, spirituality and on the list goes. We want him to have a strong core of self esteem and a joyful love of life so that if, for example, future school years bring harsher teasing -- as so many parents of children who stutter have reported -- he will have reserves of confidence and happiness within to call upon. What child in this world does not need this?

I emphasize the importance of combating vulnerability and fear and strengthening parent and child from within because I believe it has to be the foundation of providing the appropriate care and support for a child who stutters and his or her family. This strength can come from friends, support groups like NSA, faith and prayer, and enjoyment of all the good life has to offer. There is no delusion on my part that stuttering will not cause deep wounds and be a great struggle. In fact, it is because I recognize this that I am so committed to strengthening our core.



There are three other beliefs I would like to share with other parents. It was after reading textbooks, studying websites and talking to many families and therapists that I formed these beliefs, which I am presenting in order of importance.

First, we must assume that stuttering is a condition that Logan will live with the rest of his life and prepare him and ourselves based on that assumption. If that assumption proves wrong then all the work we will have done to strengthen him will help him with any challenge he may face. This was the hardest conclusion for me to reach because I focused for so many months on searching for the

"cure" to make this go away. I am still on that search, but it does not drive our treatment of our son.

Second, we must continue with therapy so that Logan can manage his stuttering both physically and emotionally. This is the hardest conclusion to follow through with because there are so many different therapies and it is very hard to know which to do and in what order. Logan has been in speech therapy for 3 years. Is it helping? It is hard to know because we do not know how badly he would stutter if he had not been in therapy. Yet we do believe he has been emotionally supported and has been given tools to help him. What we struggle with the most is how active we should be at home with instructing him on using his tools. We want his home to be a sanctuary where he knows he is unconditionally loved and does not have to be self conscious about his speech. Yet he wants to improve his speech and we want to help him. So we are going to investigate the Lidcombe Program and then make a decision on whether to use it.

We also struggle with the question "what else should we be doing?" We have decided to have Logan see a neuro-psychiatrist. We are very reluctant to even consider medication, but we feel we should not shut that door before we know what is there to evaluate. We also fear going overboard with psychiatric treatment given that our son is a very well-adjusted child who is excelling in school, has many friends and is coping well, at least so far, with his stuttering. We also are aware that there are numerous other therapies and programs, such as the fluency shaping therapy offered at Hollins Communication Research Institute and the Airflow Method offered by the National Center for Stuttering. Then there are the devices, like SpeechEasy. It is easy to feel overwhelmed and to not know what to try and in what order, at what age. We are in the process of further investigating the theories that underlie these various treatment protocols and devices and then we will map out a plan based on what feels right for our family.

Third, I believe everyone touched by stuttering should actively support efforts to identify the cause(s) of stuttering and develop a cure. I want to know who is studying stuttering and what they need from us. To read about NSA member Dr. Gerald Maguire, a stutterer on a quest for a cure, Google him or go to:

<http://stuttertalk.com/2008/08/18/gerald-maguire-episode-51.aspx>

If you have any advice on "what to do and in what order" or can inform me of current research efforts to find the cause of stuttering and ultimately a cure, please email me at shunter@tampabay.rr.com.

We wish all of your families strength as you continue on your journey to provide the best life for your children! ■

Stutter Buddies

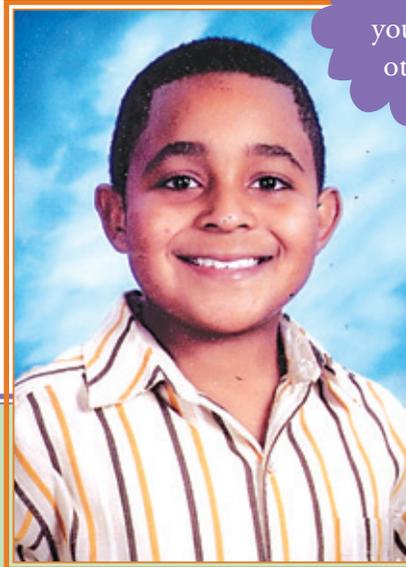
I Like to Tell Funny Stories and Jokes

by Scott W.

Hi, My name is Scott and I am 8 years old. I live in New Jersey with my Mom, Dan, brother David, guinea pig named Scooter and Japanese fighting fish named Dinko. I think I'm the only one in my school who stutters. My brother stutters too. I am in the second grade. I am a Cub Scout and like to fish, sing, ski, play baseball, and tell funny stories and jokes. ■



“Scott, Thomas and Anna... you are an inspiration to other kids who stutter! Thanks!”



Expressing Myself

by Thomas J.

My name is Thomas Jones and I am 8 years old. I live in Bayside, NY. I am in the third grade. I have been stuttering since I was 3 years old. In the last 2-3 years it has gotten better with the help of my Speech-Language pathologist. Although I stutter I don't let that stop me from expressing myself. I am very sociable and I love to meet new friends. I am not shy at all. At my uncle's 50th birthday party I said Grace in front of 150 guests. I was not afraid and I did very well. In the beginning of the school year with the help of my therapist, I wrote about stuttering and what it felt like to stutter and I read it to my class. I wanted them to understand what children and adults like me feel like when we stutter. They now understand me and when I'm having a rough time speaking they are very patient with me. It was very informative for my teachers as well. At the end of my speech one of my classmates informed me that his mother stuttered til the age of 14 and now she's a professor at Queens College. Although I stutter, I love who I am. ■

Stuttering

by Anna C.

Sometimes I stutter. There is a lot to learn about stuttering. Use easy beginnings to help you get going. Tension causes stuttering. Talking about stuttering helps. Every now and then stuttering comes and goes. Really cool people stutter. I will be the best person I can be. Nothing can stop people that stutter from achieving goals. Going to speech helps.

I am 9 years old and in third grade. I do softball in the summer and I do dance and gymnastics. I've been stuttering since first grade. I went to a stuttering camp last summer. It was awesome because I learned a lot about stuttering. ■

Stutter Buddies



Just Because I Stutter

by Brady G.

Don't think I'm weird and talk about me
Don't pretend to be me
Still ask me I might talk to you
Just because I stutter
Doesn't mean I can't talk
It doesn't give you the right to laugh
It doesn't stop me from having conversations
Just because I stutter
Can't wait 'til I get better at talking
Just because I stutter-please still talk to me. ■



"Thanks Brady and Adam for sharing your thoughts with us. Great articles!"



Rucus, Angel, Notes, Hoosier, and Tech



Family Voices would like to hear from YOU!
Please send us your thoughts, ideas, questions and stories.

Contact the NSA or Sarah D'Agostino at sdowgiallo@yahoo.com

Stutter Buddies Stories and drawings may be submitted for publication. Send them to the NSA or to Bonnie Weiss at 1484 Kensington Avenue, Buffalo, NY 14215 blweiss1@verizon.net



My Journey with Stuttering

by Adam S.

Hi. My name is Adam. I am 9 years old and in 4th grade. I live in Collegeville, Pennsylvania and I go to South Elementary School. I stutter. I started to go to speech in kindergarten, but I did not go to speech because I stuttered then. It was because I couldn't say some speech sounds correctly. Then in first grade I started to stutter. I wasn't worried that much because I didn't know exactly what I was doing but had the best speech teacher ever, so I was still going to speech class. My stuttering was not that bad in first grade. But then in second grade it got very bad, and that's when I knew what stuttering was. The worst thing about stuttering is sometimes when I try to say something important, people can't even hear what I say. So, that makes me feel very bad. I usually stuttering on the "c" sound so it's very hard to say c-c-c-c-c-clock, c-c-c-c-c-cat and other things. However, over the last week or so I have been suddenly starting to talk more easily. I am not stuttering so much anymore. The thing is I'm really not sure why my stuttering is getting better. This is what is so frustrating about stuttering. I've been working on strategies to help with stuttering since first grade so maybe now they are starting to work. I think before when I was taught strategies, I thought I was going to sound weird. But the more I practiced, I realized my speech actually sounds better and normal when I use them. Now my friends are not making fun of me and not finishing sentences for me. My journey with stuttering so far has been crazy, and I still stutter sometimes but that is okay. ■



You are not alone. We are here to help.

First NSA Youth Day in Florida and NSA Makes History with 180 in Attendance at USF for CEU!

Tampa, Florida was treated to two special events on January 16 and 17, co-sponsored by the NSA and the University of South Florida's National Student Speech-Language-Hearing Association (NSSLHA) chapter. See the NSA website— Latest News article to read about the great event. ■



Join the TAC: cont from page 1...

the teens when I was younger. However, at the rate the conference is growing its becoming to be impossible to really get to know everyone!

Outside of the conference during the year it's a little less tense. We communicate through email 99% of the time, and sometimes a phone call here and there. The NSA board often likes to hear the teens input on things, and the TAC is their main source of getting the young and hip opinions (don't deny it board members, you can't always keep up with the ever changing teen brain). Email is a necessity to being a TAC member, and you must be consistent and quick with emailing back, especially as it gets close to the conference.

Outside of the NSA, the TAC is an advantage, and I like to brag about it as much as I can. I've used it on everything from job applications to college applications, and it hasn't let me down yet. I guess employers and colleges like people who have responsibilities, who knew? Overall, the TAC is a very carefully selected group of people and it may seem cool to be in it and be a part of it, but you really have to be dedicated to it. It is a lot of work but in the end it is always worth it to hear those genuine thank you's from parents and see how the kids look up to you and watch them grow into future TAC members. ■

**NSA-Kids and TWST chapters across the US!
Check the www.WeStutter.org
for contact information!**

**family
Voices**



**Marybeth's
Message:**

Marybeth Allen,
CCC-SLP- BRP-FD

Hi Everyone! The countdown to the Arizona NSA Conference has started...but that kind of fun and experience can

happen for teens/kids/parents all year long when you are connected to a local NSAKids or NSA TWST group as you can see below in some of their monthly reports of three of these groups! These reports are just a hint of what happens when kids and teens who stutter get together with the parents, SLPs and other adults who support them.

Marybeth, Family Programs Co-Chair

APRIL 2009 - NSAKids Chicago. After meeting together, this group of 4 families and 2 SLPs, split up: parents in a discussion group with SLP Mark Allen and the kids with SLP Stephanie Hirsch, where they competed in a paper airplane contest Airplane contest ??? The kids brainstormed summer speech goals, and then worked intently on their airplanes and somewhere on each plane they included their summer goal. Then came even more fun...They competed in the categories of farthest distance, most artistic, best trick move and structural design. Stephanie reports, "We had a blast flying our speech goals!" Meanwhile, Mark and the parents discussed ways in which summer vacation has affected the children's speech fluency and freedom in the past, and explored ways to

support them throughout this upcoming summer: highlighted were: the value of educating extended family members about stuttering during "visits" stuttering & providing them with suggestions for ways to be supportive.

March 2009 - Low Country, SC NSAKids, and TWST: A spring theme highlighted this meeting of 2 teens and 2 kids and families (even grandparents came!). After playing a "How many Hershey Kisses in the plastic Easter egg game" so we filled a plastic see through egg with Hershey's kisses and everyone guessed how many kisses were in it. After the opening words spoken by a teen, and a hotdog dinner, they played pictinary: girls vs. boys!!! The boys won by 2 points, but of course everyone was a great artist! The closing words we read by one of the kids, who just a few short months ago would not volunteer to read without having the leader to read them with him.

APRIL 2009: The Sacramento/Roseville, CA NSA TWST. After pizza, the meeting was then kicked off by one of our newest members reading the welcoming words, and then a break-out, with leader Nancy (SLP) and the "kids" playing "backwards" word games and art activities. The kids were able to play together and just be kids while talking about stuttering being just one part of whom you are not all that you are and not to be defined or restricted by stuttering. Meanwhile, co-leader Sean and Paul (another adult who stutters) led a Q&A session with the parents. The parents found out what it was like growing up as a person who stuttered and what tips they could pick up from them. ■

NSAKids and TWST GROUPS...

- Dallas, TX
- Longview, TX
- Mesquite, TX
- Rochester, NY
- Low Country, SC
- Lafayette, LA
- Sacramento/Roseville, CA
- Chicago/Naperville, IL
- Illinois State University, IL
- Chicago/Skokie, IL
- Orlando, FL
- Auburn, NH
- Jersey Shore, NJ
- Southeast, MI
- Milwaukee, WI
- Queens, NY
- Rockville, MD
- Ft. Lauderdale, FL

UP & COMING GROUPS...

- Long Island, Nassau Co., NY
- Long Island, Suffolk Co., NY
- Brooklyn College, NY
- Phoenix/Scottsdale, AZ
- Tampa, FL

FAMILY VOICES is published by National Stuttering Association through the collaborated efforts of Bonnie Weiss, Gary Rentschler, Marybeth Allen, Debbie Nicolai and Sarah D'Agostino, as well as the many NSA members who wrote letters and articles for inclusion.

FAMILY VOICES is a forum for views and information about stuttering directed toward families of the NSA. The opinions expressed are those of the individual contributor, and are not necessarily the opinion of the National Stuttering Association. The NSA accepts no responsibility for the accuracy of any opinion or information provided by the contributor, nor do we endorse or reject any therapeutic strategies, programs or devices mentioned in these pages.

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