Letter From The CEO

Over the past few weeks, I've taken some time to reflect on the very short life of the Williams Syndrome Changing Lives Foundation. Likewise, I've taken some time to focus on the future of this 100% volunteer organization and its impact on the Williams syndrome community.

Since our inception, in the spirit and mission and with minimal funding, we have been able to assist several families:

Providing a weighted blanket, educational tools and resources (necessary for home schooling) as well as sensory/developmental tools for a very developmentally delayed child with Williams syndrome and cerebral palsy.

Providing a therapeutic ball chair for a dually diagnosed child with Williams syndrome and autism. The chair promotes good posture and balance while allowing movement for children requiring sensory input as well as those with ADHD.

Providing a child with a weighted blanket, Moggies™ Noise Reduction Ear Muffs (necessary due to hyperacusis) and homeschooling resources for a child with Williams syndrome dealing with extreme anxiety and behavioral issues.

In a short time, with the help of our partners and with minimal funding, we have been able to impact the lives of several families affected by Williams syndrome. This, of course, does not include the many families we have helped through guidance and resources we have provided for free (and without membership) through our website. We will continue to provide relevant information, support and resources to the Williams syndrome community as we expand.

It is important to note that while our focus is within the United States, we’ve also begun to develop relationships with organizations across the globe to increase awareness about Williams syndrome.

Stay tuned...

Penny Perez
Penny Perez
Founder and CEO

Feb/Mar 2013
New Williams Syndrome Clinic

In October 2012, a new Williams Syndrome Clinic opened at All Childrens Johns Hopkins Hospital in St. Petersburg, Florida.

The clinic will see patients quarterly. The subspecialties available are:

- General Pediatrics
- Developmental Pediatrics
- Cardiovascular Genetics
- Pediatric Cardiology/Adult Congenital
- Pediatric Nephrology
- Pediatric Endocrinology
- and Pediatric Gastrology

For more info contact Deborah Reinthaler at 727-767-6483.

Parent Resource Guide

Be sure to visit our website at www.wschanginglives.org/Medical_Resources.html to download our Parent Resource Guide.

We hope that you find this as a valuable tool for parents and caregivers. Visit our site for this, and more useful information and tools for parents, caregivers, educators and therapists.

Book Drive

We had incredible success with our first Book Drive. We've collected well over 2,000 books thus far thanks to incredible community involvement. We have already surpassed our fundraising goal and are still receiving items.

Expect more book drives throughout the year!

No Matter What's Missing.... We're All Perfect!™

Our new T-Shirts are now in the Changing Lives eStore on our website.

We carry both adult and youth sizes. Sizes run from youth Small to adult XL. Visit our website and get yours today! www.wschanginglives.org/Store.html

May is Williams Syndrome Awareness Month

May is approaching fast! What are your plans to spread awareness about Williams syndrome? Are you planning a Walk for Williams, an awareness campaign at your school or place of business? Have you reached out to your local community to get them involved?

We would love to hear your ideas and help you in your efforts! Whether you are planning a small or large event, we can provide you with resources to make your event successful. Contact us at info@wschanginglives.org to start planning your event today!
Change a Life Campaign

The Change a Life Campaign is a point of purchase program that can be a great way to obtain donations as well as an awareness campaign. This highly visible fundraising campaign can be implemented into your local community.

How does the campaign work? We will provide the cards to you. Contact local businesses, schools, banks, etc and introduce them to Williams Syndrome Changing Lives Foundation and explain our campaign. Employees/staff ask customers at the point of purchase to buy a postcard for a minimum of $1.00 (they can donate more) to help the store support Williams Syndrome Changing Lives Foundation. The customer signs his/her name or the name of a loved one on the card. Store employees post the cards pieces throughout the store/location.

Where: Banks, gas stations, grocery stores, fast food outlets, convenience stores, video stores, warehouse stores, large retail outlets, restaurants, schools, etc.

What's in it for the company and stores? The Change a Life campaign can be used to enhance employee morale and contribute to how much the company can raise for Williams syndrome. Customers will feel good about patronizing a store that gives back to its community. The Change a Life campaign is a natural public relations tool. Once the cards begin to “take over” the store’s walls, call the media. Change a Life cards are a great way to build a company’s visibility in the community.

Welcome Aboard!

We are thrilled to announce our new Director of Community Development, Tia Sager.

Tia is a Certified Therapeutic Recreation Specialist and has worked with the Developmental Disabilities population for over 20 years. She has worked with individuals with Williams syndrome since 2003 and has extensive hands-on experience with individuals with varying disabilities. Tia has been instrumental in creating various therapeutic recreational programs specifically designed for children and adults with Williams syndrome.

She will be a great asset to our team! Welcome aboard Tia!

Foundation Needs

Local Support Leaders Needed:

Our Local Support Leaders represent the Williams Syndrome Changing Lives Foundation by welcoming new families, providing support, resources and connecting in your local community regarding local medical, educational, developmental and recreational resources including specialists, schools and local social services.

Coordinating local events can be a great way to connect and support as well as become a voice for the Williams syndrome community. Interested parties should email info@wschanginglives.org.

Monthly Contest

We are giving away a set of Anytime Go Together Cards from Super Duper Publications!

To enter and for contest rules visit our website: www.wschanginglives.org/Educational_ Information.html
What is Therapeutic Recreation?
Therapeutic Recreation is the use of recreation and leisure services and activities to improve or maintain physical, mental, emotional, and / or social functioning to assist individuals with varying needs in developing lifetime leisure skills that allow them to achieve their full potential. Therapeutic recreation services are delivered by qualified professionals with training and education in therapeutic recreation/recreational therapy service. The professional certification designation is Certified Therapeutic Recreation Specialist (CTRS)

What are the benefits of Therapeutic Recreation?
Physical functioning:
• Improves perceptual motor skills, balance, agility and coordination skills
• Increases flexibility, strength and endurance

Cognitive functioning:
• Increased focus and attention span, problem solving skills, critical thinking, organization, sequencing and decision making skills

Communication & Social Skills:
• Improve skills in making choices, making requests, sustaining conversation, assertion and cooperation, strengthens & enhances friendships & social support networks, promotes greater self-reliance, helps to manage stress & anxiety and can directly impact successful transitions in community
• Enjoyable activities and social relations are significant in promoting the quality of life and productivity of the individual with a disability. Recreational therapists offer individuals with disabilities the opportunity to establish/re-establish skills for successful social integration. In addition, the therapist will employ treatment modalities which promote physical skill development, enhance feelings of well-being, foster successful experiences, facilitate continued involvement in the rehabilitation process, and establish new life activities for continued growth.

How are Recreational Therapy services different from other therapies?
Recreational therapy embraces a definition of "health" which includes not only the absence of "illness", but extends to enhancement of physical, cognitive, emotional, social and leisure development so individuals may participate fully and independently in chosen life pursuits. The unique feature of recreational therapy that makes it different from other therapies is the use of recreational modalities in the designed intervention strategies. Recreational therapy is extremely individualized to each person, their past, present and future interests and lifestyle. The recreational therapist has a unique perspective regarding the social, cognitive, physical, and leisure needs of the individual. Incorporating client’s interests, and the client’s family and/or community makes the therapy process meaningful and relevant. Recreational therapists weave the concept of healthy living into treatment to ensure not only improved functioning, but also to enhance independence and successful involvement in all aspects of life.

How does Therapeutic Recreation help an individual with WS?
Specific to individuals with Williams syndrome, we are able to address many of the leisure, social and life skill issues in a fun and realistic environment. Activities in the community require planning, organization, money management, social appropriateness, problem solving, and communication skills to name a few, but they are learning these skills in a safe and structured environment. Many life skills can be taught individually or in small groups; grocery shopping, cooking, laundry, scheduling transportation, time management are all areas that can benefit with recreation therapy. Many of the skills overlap, which is real-life training.

How do I find a CTRS?
• www.atra-tr.org/affiliatecouncildirectory.htm is a website for the American Therapeutic Recreation Association (ATRA) and provides a list of contacts for state chapters for recreation therapy
• Check with your local park & recreation centers
• NTRS (a branch of the National Recreation & Park Association).

E-mail: NTRSNRPA@nrpa.org
Phone: 703-858-0784, 22377
Belmont Ridge Rd., Ashburn, VA 20148
• Check with local university’s to see where Therapeutic Recreation programs are. (Students need volunteer and service hours during their coursework)
Anxiety in Williams syndrome
by Dr Debbie Riby, Dr Jacqui Rodgers, & Dr Mary Hanley

It is recognised that both children and adults with Williams syndrome (WS) can be more prone to anxiety than people who do not have WS. A number of research studies have revealed high levels of anxiety and incidences of fears and / or phobias in children and adults with the disorder. Indeed some children might show more fears than children with other forms of intellectual difficulty, and more than children who are developing typically. It has also been suggested that there are some types of anxiety symptoms that are particularly common in WS; therefore these might be disorder-specific. For example, our own research has reported a high incidence of separation anxiety disorder, generalised anxiety disorder and the fear of physical injury. We have used interviews with parents as well as standardised parent questionnaires to ask questions about their child’s behaviour and anxieties. For example, when probing separation fears, parents have reported in interviews that their child becomes anxious when faced with being separated from them or worried about their health and well-being. These are just a few types of anxiety that might be more prevalent in WS than in other disorders or in typical development.

Conversely, individuals with WS might be no more prone than other children to some forms of anxiety, such as social anxiety or obsessive compulsive disorder. However, we must remember that every child will be different in the type of problems they face and the way they cope with their anxieties. Furthermore, anxiety may change with age and so it is important that these issues are monitored and followed-up for individuals with WS. There will be different challenges in an individual’s life at different time points and these challenges or changes of routine (e.g. starting secondary school, challenges of adolescence) might impact upon the presentation of anxiety symptoms. Therefore we should be mindful of the specific needs of an individual in relation to what is happening in life at that time and how this might evolve with age, experience and life challenges.

Research from our group has gone a little further than merely describing which types of anxiety might be more or less prevalent in WS, to also consider anxiety in relation to other behaviours; specifically repetitive behaviours / routines and sensory processing issues (e.g. aversions or fascinations with sound). In other developmental disorders such as Autism there appears to be a relationship between anxiety and the presence of sensory sensitivities and the presence of repetitive behaviours. It appears that for some individuals sensory difficulties (like fear or aversion to sounds) may contribute to the development of anxiety and that engagement in repetitive behaviours may then provide a ‘calming’ response. It is therefore clearly important to explore the relationship between anxiety and other aspects of behaviour in order to understand the impact of anxiety on a child's everyday life and also the wider impact upon the family. There is no doubt that coping with a child’s anxiety can be a major challenge for the whole family. Therefore, access to appropriate support networks and intervention strategies is critical.

So, why should we focus on anxiety in relation to understanding WS and the impact that the disorder might have on an individual and their family? If we can find out more about the type of anxieties, fears or phobias that are experienced by children or adults with WS then this will be extremely important in a clinical setting; leading to the development of appropriate assessment methods and interventions that are purposefully targeted to the needs of individuals with WS. One of the challenges that remains for researchers and clinicians is to characterise the nature of anxiety associated with WS for both children and adults and to then consider how best to design WS-specific intervention programmes that will minimise the impact of anxiety for the individual and for their family. There remains some way to go in meeting this aim and providing the support that is needed for families affected by anxiety and this issue should be given research and funding priority due to the positive impact that providing appropriate support could have for WS families.

Dr Debbie Riby
Dr Jacqui Rodgers
Dr Mary Hanley

Continued...
Selection of references for published research on anxiety and Williams syndrome


Our Research and Research Group

We are a group of academics, clinicians, researchers and students primarily at Newcastle University (UK), studying behaviour and psychopathology associated with Williams syndrome. For more information please see our webpage or follow our work on Facebook (Newcastle WS Research Group) and Twitter (@Newcastle_WS).

www.ncl.ac.uk/psychology/research/WilliamsSyndrome/contact

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Dr Jacqui Rodgers in in the Institute of Neuroscience, Newcastle University, UK

Dr Mary Hanley is in the School of Psychology, Queens University Belfast, UK

Contact details: Dr Debbie Riby, deborah.riby@newcastle.ac.uk

Assistance Program

Financial assistance for medical needs, including costs associated with travel to Williams syndrome specialty clinics throughout the United States, specialized medical equipment, therapy sessions, specialized educational needs, specialized camps (including music and summer camps), assistance for specialized in-home care and ABA (Applied Behavior Analysis) services.

Costs associated with service and/or companion animals, nursing services, assistive technology devices, prescribed medications, specialized car seats, specialized formula and therapeutic feeding tools.

Medical and developmental resources, such as costs associated with treatment from a Developmental Pediatrician and/or behavioral therapy.

All goods, services and financial assistance is limited to individuals with a documented diagnosis of Williams syndrome. Recipients will be required to complete an application for assistance.

You can download an application at www.wschanginglives.org/How_We_Can_Help.html.

All applications will be reviewed by our committee for completeness and applications will be approved based on:

- Receipt of required documentation
- Documentation of need
- Priority of need
- Availability of funds

Help Improve Our Newsletter

We hope you’ll enjoy this newsletter and our future issues. We are always looking for ways to improve. If you have any comments, suggestions for content, or feedback on how we can make this resource even more useful to you please let us know.

Please contact penny@wschanginglives.org with your feedback and comments.
Call for Volunteers

The Williams Syndrome Changing Lives Foundation (WSCLF) was formed to enhance the lives of children and adults living with a diagnosis of Williams syndrome by providing needed financial assistance with medical, therapeutic, recreational needs and other developmental resources. In addition, the WSCLF provides support for individuals, parents and families through support, outreach and sponsored functions.

We are a fully volunteer based organization with no paid positions. We are unable to fulfill our mission without the help of a strong and committed volunteer network. With your help, we can enhance the lives of individuals with Williams syndrome, educate and build more awareness, and reach out to more families so that they can connect with others in their area.

There are many opportunities to volunteer for WSCLF. Our main need at this time is for people in every area of the nation to help connect with families. For more information please contact: info@wschanginglives.org

We’re taking the Polar Plunge

We are raising money for Special Olympics because we believe in their mission to provide year-round sports training and athletic competition to children and adults with Intellectual Disabilities throughout South Carolina.

As an organization assisting individuals with special needs, we feel it is important that everyone has a chance to succeed and we believe that Special Olympics does that.

We will have several representatives from our organization ready to take the plunge and hope to have your support.

Please share this with your friends and family and come take part in this exciting day.

For more info and to donate: www.firstgiving.com/fundraiser/ws-changinglivesfoundationha/lake-murray-polar-plunge