



1p36Deletion SUPPORT & AWARENESS

President's Message

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As most of you know 1p36 Deletion Support and Awareness is a completely volunteer run and supported organization. We could not function without the fantastic and unending support of all of you. This was especially evident last fall in the wonderful support that was shown during the Chase community giving Facebook campaign.

Because of our friends, family and supporters we were able to come in 85th place and win a \$25,000 grant from JP Morgan Chase. We received the money in early February and will use it to further our cause and accomplish our mission of helping individuals affected by chromosome 1p36 abnormalities overcome the obstacles they face to be able to lead healthy, happy and productive lives by providing support and education to their families and increasing awareness of chromosome 1p36 abnormalities in the public and medical community.

Ken Shirtcliff
President, 1p36 Deletion Support & Awareness

2012 1p36 DSA Conference Scholarships Announced

We're excited to announce that due to the hard work and generosity of Julie and Jason Friedman and their annual 1p36 DSA scrapbook fundraiser, 1p36 Deletion Support & Awareness is able to offer 4, \$650 scholarships to this year's conference.

The scholarships are meant to allow families who have never been able to go to a 1p36 DSA conference in the past have the opportunity to attend. There are a few requirements to be eligible.

Click the link below to find out more and complete the online application. All applications must be received by April 22nd, 2012.

[2012 1p36 DSA Conference Scholarship Application](http://www.1p36dsa.org/2012-conference-scholarship/)
<http://www.1p36dsa.org/2012-conference-scholarship/>



Check out what some 1p36 parents are up to across the

globe: *Here is an email we received from Down Under and wanted to share. If you have news to share with us, please email us at info@1p36dsa.org. We would love to hear from you and to share your news with rest of the 1p36 global community!*

Greetings from Australia.

Just a quick note to let you know we've put a link to your website from ours, www.info4carers.com. It's in our "Resource Directory" under the "Disability Chronic Illness Specific" section.

Our son was diagnosed with 1p36 deletion syndrome. We've compiled a free book called "You Are Not Alone - A Carer's Journey" to help other

families such as ourselves. The book was recently printed with a 8,000 copy print run with the assistance of the Cerebral Palsy League of Queensland, Australia and Shine Lawyers, Australia.

You can also view the entire book from our website for free at www.info4carers.com, as well as some other interesting articles.

Bye for now.

David Marler, Tanya Dennis and Jaden Dennis-Marler
www.info4carers.com

Parent Experience: Back Care

Reality checks are rarely pleasant but sometimes they do help us out.

From Carrie Daggett, Mom to Kate, 1p36

A couple weeks ago I had an email conversation with another 1p36 parent about the difficulties of carrying and bathing our growing children. The conversation reminded me of something that happened about a year ago that had struck fear into my heart. This incident wasn't about my daughter Kate's many health problems; it was about one of mine.

One morning, while getting Kate ready for school, I did something that I do every day, many times a day. I simply lifted up my then eight year old to move her from one place to another. But this time, when I lifted, I immediately felt my back twinge. I ignored it because there was no way I could put her down. Kate can't stand, walk, crawl or even sit very well. But right away, a small voice in the back of my head said "this is NOT good". I finally got her into her wheelchair and out to the school bus. Imagine the stiff legged walk of someone who has a pole stuck up their back. That was me trying to avoid any movement that caused more pain. I managed to get myself to work but I sat at my desk in agony. Within an hour I admitted to myself that there was NO WAY I could work in this state. In fact, I had no idea if I could actually drive myself home again because of the pain. I thought

"At least Kate is at school and taken care of so I can go home and rest my back". It was at that moment that my cell phone rang. It was Kate's aide at school. "I'm sorry but Kate is sick and running a temperature. You'll have to come to the school and get her".

Okay, so here was my brutal reality check. I am the main caregiver of my (now) 9 year old special needs child. Don't get me wrong, my husband does A LOT! He is a loving caregiver to Kate as well. But most of the time, her care is up to me. I lift, diaper, wash, dress and feed her. I am the manager of all her prescriptions, medical supplies, doctor's appointments, IEP meetings, school correspondence, medical records and insurance. She depends on me for her whole well-being. And, now, all of a sudden, I can't do any of that. **Press Panic Button Now!**

So what did I do? My husband was 20 miles away at work. In my state, there was no way I could drive to Kate's school to get her much less lift her and her wheelchair into my van. Even if I could, I would still have to get her into the house and then care for her. I did what any other person in my position would do. I started to cry. And then, after about a minute and a half of that, I worked out what to do with help from the school and a good friend who came to my rescue.

I got myself to the doctor's office as soon as I could. The diagnosis: acute low back pain due to an over straining activity. Turns out that on that particular day I had lifted a heavy weight (Kate) very poorly. My arms were extended too far from my body and I did not lift with my legs. The next few weeks involved pain meds, missed work, chiropractic appointments, physical therapy and a lot of moaning and whining on my part.

But, all the drama could have been avoided.



Since that time, I have concentrated on making sure that doesn't happen again. I stop to focus on body mechanics every time I lift Kate. I now work on developing those core muscles that support the lower back so that I am stronger and more fit to lift my always growing daughter. I'm also working on shedding the extra weight that I carry around so that lifting and carrying Kate is less difficult. I still have a way to go but it's just like trying to teach our special kids something new. You just keep at it and at it. You celebrate every victory, no matter how small because as long as you're moving forward, you're moving forward.

Caring for Yourself So You Can Care for Your Child

Perhaps the only thing worse than the thought of losing your special needs child, is the thought that something will happen to keep *you* from caring for them. Whether or not your child is as physically involved as my Kate, I hope you can benefit from this

information and avoid a similar back pain experience like mine.

Here are some tips for proper lifting whether it is a child, a wheelchair or a sack of potatoes:

- **Focus** – before you lift, think about if your body is proper alignment and concentrate on tightening your core while lifting to protect your back.
- **Do not over extend** your arms from your body while lifting. Try to keep what you're lifting as close to your core as possible.
- **Place your feet shoulder width apart** so that you have a strong base.
- **Bend your knees** and do not hunch your back forward. Keep your core tight.
- **Try to avoid twisting and bending** when you lift. This is not always easy so if you have to twist, keep concentrating on those core muscles staying tight and the back muscles locked in strong.
- **Commit** yourself to strengthening your core. A strong core means a strong back.

Strong Core Muscles are Key

I've been very fortunate to have the help of a personal trainer, Jon Farrell at Columbia Athletic Club, to help me get stronger and healthier so that I can be a better caregiver to Kate. Jon graciously agreed to write up some tips on how we can all work on strengthening our core muscles at home. Here is what he had to say:

As a personal trainer I see clients from all walks of life, each with unique backgrounds and different stories to tell. However, despite the myriad of differences between my clients one common thread unites them all, and that is a desire for a strong core which leads to a healthy and pain free lower back. Simply put, if you desire a strong a healthy back, one that is not plagued by aches and pains, and one that can easily withstand the challenges of child rearing, you must train the entire core region of your body. In doing so you will gain greater

strength, stability, enhanced motion and maneuverability, and especially relief from back pain!

So just what is the core and how do we train it? A few of the muscles included in the core are:

- the transversus abdominus (the main muscle in our stomach that we consider to be our "abs")
- our internal and external obliques (the "sides" of our abs),
- the pelvis,
- erector spinae (the muscles commonly associated with the lower back),
- the glutes,
- and the entire shoulder girdle.

Quite a few muscles! All of these and more make up one's core and if trained properly can help increase core strength and stabilization and help prevent and treat low back pain.

There are several ways to strengthen the core, and in the following I will describe several methods and exercises that can be easily employed for such a task.

1. Stabilization Training: This essentially involves doing as many exercises as possible in unstable, yet controlled, environments. For instance, rather than simply standing with both feet on the ground while doing a bicep curl or a shoulder press, try standing on one foot, or perhaps on a Bosu ball or some other squishy surface. Doing so will greatly challenge the muscles in your core and help them to grow stronger.

2. Lower Back Exercises: Here are three easy exercises that can be performed in the comfort of one's home that do not require any extra equipment. All three will target the core but especially the muscles in the low back, helping to strengthen them and prevent injuries.

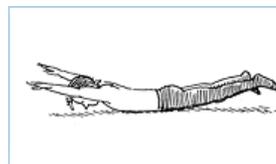
a) Floor Plank: Lie flat on the floor with your head facing the ground. Using your arms, raise yourself off the ground so only your hands are on the ground as well as your toes. The shoulders should be directly over your wrists, and the navel needs to be drawn in to your abs. If this motion is too difficult, try lowering yourself so only your forearms and toes are touching the floor, while the rest of your body is suspended in the air.



b) Floor Bridge: Lay on the floor on your back with your knees bent and the heels close to your glutes. With arms flat at your side lift your hips while keeping the navel drawn in to the abs, pressing the feet and arms into the floor. Try to engage the back, especially the lower back, and focus your attention on squeezing that area. To increase the intensity of the exercise, try using only one foot to lift yourself off the ground or place an object under both feet to allow you greater range of motion.



c) Superman: Lie flat on the floor with your head facing the ground with your legs and arms spread slightly. Lift the chest, kneecaps, and thighs off the ground so the only part of your body still touching will be part of your abs and hips. The focus again needs to be on the low back, squeezing these muscles of your body. Draw the navel in to your spine will help to increase the intensity of the exercise.



Remember, you are not alone in your struggle with low back pain. Over 80% of adults in America deal with some degree of low back pain, much of which is derived from living a sedentary lifestyle with little physical activity. The good news is that lower back pain is treatable, and there are many exercises which can be done which will help strengthen your core and help reduce your low back pain now, as well as prevent increased pain in the future. Please feel free to contact me with any questions you might have, as I will be happy to assist you in your journey to better health!

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If you have a lifestyle tip, personal experience or inspiring account that you'd like to share with our readers, please contact us at info@1p36dsa.org. We'd love to hear from you!

1P36 DELETION SUPPORT & AWARENESS

E-Mail:

info@1p36dsa.org

We're on the Web!

See us at:

www.1p36dsa.org

and on Facebook at:

www.facebook.com/1p36DSA

2012 Conference Registration is Open!

The 2012 1p36 Deletion Support & Awareness Conference will be held in Gatlinburg, Tennessee, July 26th – 29th. The conference is a great time to meet other families and to hear speakers present information on topics that relate to raising and caring for someone with 1p36 Deletion Syndrome.

To learn more about this year's conference and find out how to register, click the link below. We hope to see you there!

[2012 1p36 Deletion Support & Awareness Conference Information and Registration](http://www.1p36dsa.org/2012-conference-info/)

<http://www.1p36dsa.org/2012-conference-info/>

The conference committee is still hammering out the details for the agenda and family activities so be sure to keep checking the 1p36 DSA website and our Facebook page for the latest news.

If you have any questions about the conference or need help with registration, email us at info@1p36dsa.org.



Families listening to a speaker at the 2011 1p36 DSA conference



Cindi and her daughter Callie sharing at the 2009 1p36 DSA Conference

4th Annual 1p36 Scrapbook Fundraiser & Raffle Held in Westfield, Indiana



On Saturday, February 25th Julie, Jason and Lily Friedman held their 4th Annual 1p36 Scrapbook Fundraiser & Raffle in Westfield, Indiana. It was a GREAT success! With 30 scrappers and 24 Raffle prizes, the event raised nearly \$2500 for 1p36 DSA! We are nearing the \$10,000 mark for the life of this fundraiser.

Special guests at the event included two other 1p36 families. Shane and Melissa MacKendrick traveled from the Cincinnati, OH area and were instrumental in selling Raffle tickets throughout the day. The Johnson family from Central Indiana attended as well. It was

great to meet Crystal, Matt and their amazing daughter Abby!

The funds raised at this year's event will be used to help send several families who have never attended a 1p36 DSA Conference attend this year's conference in Gatlinburg, Tennessee this coming July. More details on this 1p36 DSA Conference Grant Program will be provided in the coming weeks.

