

How To Run a Successful Event in Raising Awareness for SPD

By Ryan

In the fall of 2010, I decided to create an event that would raise money for the STAR Institute and celebrate Sensory Awareness Month in October. Since I have enjoyed biking from the time I was a child, it seemed like a natural fit to create an event centered on this activity. I asked friends, family, and the community to contribute to this worthy cause by donating funds as I biked one hundred miles to show my dedication. I have participated in charity events for many years; however, I had not had the opportunity to be on the organization and planning side. I have to admit, I was a little overwhelmed on how to pull it all together and have fun at the same time. The following paragraphs are intended to help other "first timers" get started and provide direction on making a difference.

Getting Started

Pick an activity that you enjoy. This in turn will attract others to join in with you! Perhaps your choice will be a walk, bike ride, run, swim event, or something else that involves physical activity. I found it was important to identify something fun that I was currently engaged in. Keeping things fun is important to those who will help you and also to the event itself.

I discovered some larger events require special insurance, permits, police, or local law enforcement. This aspect of planning an event can be a large undertaking to tackle alone. After researching events on websites like active.com, I decided to keep it simple in year one by biking one hundred miles solo. I asked friends to help sponsor me and promote my event via social media sites. The first lesson that I learned is the event does not need to be huge in size to make a difference. In fact, larger events equal larger operating costs. I chose to design an event that was manageable with potential to grow over time. It's important to remember that anyone can make a difference, and even small, grass root events have a meaningful impact.

Publish the Event

Once I chose the event and venue, I created a website to describe what I wanted to accomplish. Firstgiving.com has an easy user platform that allows you to upload pictures and send updates by linking to other social media sites. Along with word of mouth advertising, I promoted my first giving site via Facebook and Linked In to get maximum exposure. This was a good thing!

Ask for Help

Everyone wants and needs help in planning events to raise awareness. Sometimes, the best results are achieved in simply picking up the phone and asking. This can be intimidating; however, it often yields the best results. Be proud in what you are accomplishing by asking local businesses if they would like to participate. You may add incentive by having them mentioned on a bike jersey or press release around the event.

It's also a good idea to post messages on your Facebook page asking for direction or insight from your friends who have experience in planning these types of events. Great ideas can be shared and quickly put to use by simply asking a question.

Have Fun!

This is the most important theme to guide your event. Here's my link from last year's one hundred mile bike ride. Good luck!

<http://www.firstgiving.com/fundraiser/ryan-stille/cycling100miles4spd>

Carrrie's Story

I have to say, that I'm truly lucky because both my husband and I work with many wonderful people and we both work at financial services firms and it is the 'norm' to donate to numerous coworker events throughout the year.

I'm also fortunate that my husband's company has an automatic match for any donation of \$50 and greater. My company has a Corporate Giving group and donates up to \$1000 for a cause, depending on the employee's involvement.

I'm just lucky to be surrounded by and supported by so many. I didn't get permits, or permission or anything like that because it was just my family and I out on a walk.

Here is the original email I sent to my family and friends:

Dear friends,

On October 30th, I am organizing a walk to raise funds for an amazing organization, which is working hard to make a huge difference in the lives of so many children, including my own – The STAR Institute. By walking, I hope to raise awareness about sensory processing disorder (SPD) and the effect it can have on children and their families.

Sensory processing is a term that refers to the way the nervous system receives messages from the senses and turns them into appropriate motor and behavioral responses. Whether you are biting into a hamburger, riding a bicycle, or reading a book, your successful completion of the activity requires processing sensation or "sensory integration."

Sensory Processing Disorder (SPD) is a condition that exists when sensory signals don't get organized into appropriate responses. SPD has been described as a neurological "traffic jam" that prevents certain parts of the brain from receiving the information needed to interpret sensory information correctly. A person with SPD sometimes finds it

difficult to process and act upon information received through the senses, which creates challenges in performing countless everyday tasks. Motor clumsiness, eating difficulties, behavioral problems, anxiety, depression, school failure, and other impacts may result. Without proper treatment and knowledge, SPD can make daily life, learning and some of the typical joys of childhood very difficult for many children.

Studies estimate that at least 1 in 20 children has SPD. Symptoms of SPD, like those of most disorders, occur within a broad spectrum of severity. While most of us have occasional difficulties processing sensory information, for children and adults with SPD, these difficulties are chronic, and, without treatment, they disrupt everyday life.

This is where the STAR Institute comes in – the organization is a tireless advocate for our children with SPD. The STAR Institute is committed to conducting research into the causes, diagnosis and treatment of SPD. They provide amazing resources for those with SPD and their families, as well as to health care providers, policy makers and the public. The STAR Institute is one that is near and dear to our hearts and one that we've actively supported since we became aware of SPD two years ago. This past year I had the pleasure of spending an evening with the founder and lead researcher of the STAR Institute, Lucy Jane Miller, as well as participate in her Parent Think Tank - a small group of parents working directly with the SPD Foundation. This experience has increased our confidence in and support of this organization. We've also seen, first hand, how incredibly effective and life-changing appropriate treatment can be.

I hope that you will consider taking the time to fill out the attached form to make a donation. You can email me, call me, or mail me the information. I will do anything to make it as simple as possible for you. Cash, credit or checks are all accepted – but there is no ability to donate directly online at this time. However, you can donate generally to the STAR Institute here: spdstar.org/donate-to-star

While my primary goal is to raise funding for the STAR Institute, I recognize that everyone has different charities that they support. So, equally important, I also hope to simply make more people aware of SPD, because, right now, not enough people know about it or understand it. This leads to misdiagnosis and misunderstanding – and, worst of all, incorrect or lack of treatment. Please feel free to forward this email to others and if you would like more information about SPD visit spdstar.org .

Thanks for taking the time to read this email and please pass it on!

Carrie

P.S. If anyone would like to participate in the walk or in raising funds for the STAR Institute, just let me know.

Here is the follow up email I sent along with a poem:

Hi Everyone – I want to thank everyone who has generously donated to the STAR Institute and supported our walk. Equally important is to thank and acknowledge so many of you who reached out to share a story, asked about a child you know who has sensory struggles, or just simply wanted more information on SPD generally...as I said, spreading awareness is so important!

Our walk is this weekend, so I thought I would send out a quick message of thanks and remind you that there is still time to donate. Please see my original email for more information. And, I also wanted to forward this amazing poem that sums up a child who has SPD. Please take a few minutes to read it. It's truly touching...

The Misunderstood Child A poem about children with hidden disabilities
by Kathy Winters

I am the child that looks healthy and fine. I was born with ten fingers and toes. But something is different, somewhere in my mind, And what it is, nobody knows.

I am the child that struggles in school, Though they say that I'm perfectly smart. They tell me I'm lazy -- can learn if I try -- But I don't seem to know where to start.

I am the child that won't wear the clothes Which hurt me or bother my feet. I dread sudden noises, can't handle most smells, And tastes -- there are few foods I'll eat.

I am the child that can't catch the ball And runs with an awkward gait. I am the one chosen last on the team And I cringe as I stand there and wait.

I am the child with whom no one will play -- The one that gets bullied and teased. I try to fit in and I want to be liked, But nothing I do seems to please.

I am the child that tantrums and freaks Over things that seem petty and trite. You'll never know how I panic inside, When I'm lost in my anger and fright.

I am the child that fidgets and squirms Though I'm told to sit still and be good. Do you think that I choose to be out of control? Don't you know that I would if I could?

I am the child with the broken heart Though I act like I don't really care. Perhaps there's a reason God made me this way -- Some message he sent me to share.

For I am the child that needs to be loved And accepted and valued too. I am the child that is misunderstood. I am different - but look just like you.