

CIDSO Meeting Minutes

April 3, 2017

Attendees:

Diane Crutcher	Angela Hedican	Judy Bates
Kim Weber	Steve Newbold	Dawn Mattia
Kathy Peden	Shelley Marquis	Wendy Boswell (Via telephone)
Hollis Peden	Sandy Ginther	
Deb Presley	Lisa Martin	

Quorum

There are currently 67 CIDSO members. 14 members were present at the meeting therefore a quorum was established.

Approval of Minutes

Motion was made by Diane Crutcher to approve CIDSO Minutes from the Annual Meeting, held January 2017. Motion was seconded by Hollis Peden. Minutes were approved.

Treasurer Report

- Account Balances and Cash Flow for first quarter 2017 were presented. Assets in all accounts totaled approximately \$135,000.
- It was determined that the check from United Way was from Steve Newbold's donation through his employer.

Conference Report

- Angela Hedican attended the NDSS Buddy Walk Conference and Down Syndrome Affiliates in Action Leadership Conference.
 - Angela shared valuable information she gathered at the conference, notes are attached.
- Kim Weber attended the NDSS Buddy Walk Conference
 - New ideas will be implemented at the walk.

Buddy Walk Update

- Kim Weber & Angela Hedican will chair the 2017 CIDSO Buddy Walk.
- Tentative walk date is September 23, 2017.
- Kim & Angela will work to "freshen" the website.
- New posters may be made of CIDSO members

Bruegala Update

- Sandy Ginther requested additional information for the application and she will follow up to submit it in a timely manner.

Fashion Show Update

- The fashion show was a great success and featured models from age 4-56
- The venue was nice and the event was well attended.

CIDSO Gala & Open

- Gala is June 2nd, CIDSO Open is June 3rd
- Changes are being put in place in an attempt to attract more people
- Changes will be communicated with CIDSO membership

ISU Speech & Hearing

- Deb Presley will review bills as they are received

Funds Administrator

Program Funds:

- Board agreed to \$2000 in a “discretionary” category that the Funds Administrator can utilize as he/she deems reasonable without Board approval

Conference Funds:

- Fund budget is \$2000. Will address budget limit if needed

Miscellaneous:

CIDSO Picnic

- The picnic will be held on August 20th
- Anderson Park , at the large shelter by the play ground (Location is new this year)

Book Request

- CIDSO received a complimentary copy of “An Extra Ordinary Life” by Rhonda G. Penny
- Kathy Peden will read the book and report on it and then book will be given to Angela Hedican for review.

“Thank You” policy

- Board agreed that thank you for outgoing officers and volunteers will be non-financial.

Website

- Mission Statement (from FaceBook page) will be added
- Diane Crutcher, Diane Walker, and Deb Presley will update the funding information

Legal Restrictions & Funding

- Steve Newbold has reviewed the IRS Guidelines for non-profits
- In summary, a non-profit cannot be formed to benefit the board
- Steve feels the way CIDSO is handling funds is within the IRS guidelines

Treasurer’s Bond

- Bond is in place

- The bond insures anyone who has access to CIDSO funds, not just the treasurer
- Billing will be annual

Adjournment

A motion was made by Diane Crutcher to adjourn the meeting. Holis Peden seconded the motion. Meeting was adjourned.

Notes provided by Angela Hedican

Notes from NDSS Buddy Walk Conference and Down Syndrome Affiliates in Action Leadership Conference (February 2017)

1. *Opening Session (NDSS President and National Buddy Walk Director)*
 - *Focus on new vendors and fundraising ideas for local BWs*
 - *Little Caesar's is a new National Partner!*
2. *Adding a 3rd Party Fundraising Event into Team Fundraising Activities – John Gubser and Tony Thornberry (father and grandfather of a boy with Ds)*
 - *Team fundraising efforts last year included a restaurant donating a percentage of lunch and dinner receipts for one day, bagging groceries at a self-bag local store, and an annual Festivity Day at a family member's farm. Detailed information about the festivity day was provided.*
 - *Team raised \$30,000 last year.*
3. *Incorporating a 5K Into Your Buddy Walk – Bill Lawfield, Co-President, DS Association of Roanoke*
 - *Focus on LOTS of detailed recommendations for incorporating a 5K*
 - *Sponsorships and volunteers were considered most important*
 - *Stressed that doing a 5K isn't a big fundraiser, but it is very effective for spreading awareness and promoting your mission*
4. *Lightning Round – various topics – interesting ideas:*
 - *Charge a registration fee or not? Most organizers said no. Believe that it generates higher donations if you don't. Recommend having sponsors cover the cost of t-shirts or consider them to be a cost of doing business.*
 - *Self-advocate party/dance on the night before the walk.*
 - *Use social media to run contests. For example, use to promote a matching donation or enter participants into a drawing ("any team raising \$100 this week is entered into a drawing for X")*
 - *Automatically set up your twitter feed to tweet donations when they are received*
 - *Use an online auction for fundraising*
 - *Hire a college student for the 48 hours leading up to the walk and during the walk to post, share, tag, etc. to raise interest.*
5. *Online & On Fire – How to Supercharge and Streamline Your Online Presence – Jay Wilkinson, firespring.org -- print materials available*

- *SO MUCH INFORMATION, but some take-aways:*
 - *You should be able to get anywhere on your site in 3 clicks or less.*
 - *Content Management System: at least 3 people in your organization should be able to add information to your website without going to someone else to do it, using a simple drop and drag.*
 - *The number one request of users is online registration. This is not a link to a PDF for users to print and send in.*
 - *Formula for ensuring the perception of freshness of content (vitality): dated content on the front page (headline with date) + post at least every 7 days + show 3 occurrences. This tells people the site is always up to date*
 - *Nonprofits should blog! Set up a team of people in your organization who are naturally wired to write and divide and conquer.*
 - *Incorporate social media (this was covered in more detail in a later session). BUT LinkedIn is more important. Set up a “company” page for your NP; individuals should also be set up on LinkedIn. Facebook: 91% of local searchers use FB to find local organizations online; 68% of people take time to learn about a charity if a friend posts about it.*
 - *Posting consistently is key.*
6. *An Unprecedented and Exciting Down Syndrome Research Discovery Engine – The Crnic Institute Human Trisome Project – Keith Smith, Senior Professional Research Assistant*
- *The Crnic Institute is developing a biobank of information/samples of individuals with Ds and others. They believe that this project will significantly increase the speed of Ds research and the understanding of associated medical conditions such as leukemia and Alzheimer’s disease.*
 - *Seeking participants. Must provide data and samples in Denver. Some compensation is provided.*
7. *Online Tools that Help Nonprofits Learn, Listen & Engage – Jay Wilkinson*
- *Provided a list of online tools to help you be productive and build an audience: 1Password, Doodle, Springboard, Dropbox, Evernote, Picmonkey*
 - *Gave a series of steps, spending 3-6 hours one time only, to get started in building an online presence. Then, he says you need only spend 15 minutes a day on social media to maintain presence and interact/provide feedback.*
8. *Notes from Leaders’ Circle – Support Staff and Committee Members*
- *Different types of informational support you can provide: prenatal, postnatal, physician support, nurse/office staff support. This is a very grant-friendly program!*
 - *The Learning Program is offered by the Down Syndrome Foundation of Orange County. Parent and child classes. Proven, effective materials and curriculum.*
 - *Summer Employment Academy: paid school personnel to teach soft skills for job seekers; identified businesses for job shadowing*
 - *SmartStart is offered by the Kansas City Down Syndrome Guild. Kindergarten readiness program, parent-only program, behavioral topics, communication, school relationships, IEPs. After each session, “homework” or things to try.*

9. *Reach More New and Expectant Parents: Create a Customized Medical Outreach Plan!* - Heather Bradley (DSDN), Stephanie Meredith (Medical Outreach Director, University of Kentucky), Sarah Cullen (Family Support Director, Massachusetts Down Syndrome Congress) -- ppt available
 - *The National Center for Prenatal and Postnatal Resources – downsyndromediagnosis.org – includes:*
 - *lettercase.org: Online and print materials for expectant parents considering prenatal screening/testing or first receiving a prenatal diagnosis for a genetic condition; translated into 8 languages*
 - *brighter-tomorrows.org: Video tutorials for medical professionals on how to deliver a diagnosis of Down syndrome*
 - *downsyndromepregnancy.org: diagnosis to delivery materials*
 - *Be aware of the populations that you serve – materials should be visually representative and have appropriate translations*
 - *MDSC (MA Down Syndrome Congress) First Call Program is set forth as an example of family outreach*
 - *Trained parent mentors available*
 - *Collaboration with a genetic counselor*
 - *Providing hospital care and support*
 - *Identify barriers as opportunities to support: transportation, language, financial, cultural*
 - *Medical outreach – providing up-to-date, accurate resources for local providers; a strong collaboration with health care professionals will ensure more referrals to your program and growth of your organization and more families will be connected and supported*
 - *Suggestions for how to accomplish medical outreach*

10. *Raising Major Gifts in a Small Nonprofit* - Betsy Wilson (Director of Major Gifts and Planned Giving, Community First Solutions) – ppt available
 - *Start by defining what is considered a major gift at your organization*
 - *Identify and qualify prospects – start with your database. Consecutive giving is a major indicator. Look for connection and capacity to give. Need to build a relationship before asking.*
 - *Build a relationship with each donor on your list.*
 - *The right person, asking the right person, at the right time, for the right amount, for the right project*
 - *Do they want to be recognized? How do they want to communicate? Send advocates out for a special thank you visit.*
 - *There will be no. Even if there's a no, the stewardship and thanking stays the same.*

11. *Community Outreach: How to Open Doors and Educate Others* -- Christine Newlon (Public Speaker and Outreach Specialist, NADS) – ppt available
 - *Identify your DSA's community outreach goals: serving others in the Ds community (increasing the number of individuals served, expanding to other diagnoses); educating about Ds (community awareness and general knowledge, increase inclusive practices, improve interactions with medical personnel); networking (recruiting volunteers, fundraising)*

- *Identify your DSA's specific needs and target groups – identify their goals and yours – how to meet them?*
 - *Hospitals*
 - *Schools*
 - *First Responders*
 - *Businesses*
- *Work on sustaining relationships*
 - *Tailor your content to your audience and its goals (this is the hardest part)*
 - *Always include contact information*
 - *Follow up: thank you notes, supplies needed, invite to your celebrations, gatherings, family nights, etc.*
 - *Join organizations where you might see them again (Chamber of Commerce, Lions Club, Kiwanis, etc.)*

12. *Meet A New Family Where They Are At (Prenatal or Post-Birth) - Jena Wells (Early Matters Coordinator, Down Syndrome Association of Greater Cincinnati) -- ppt available*

- *Mind your cues ... take cues from the parents, try to be aware of where they are "at" in terms of processing diagnosis, grief*
- *Be aware of things you should not say (At least ..., It's God's will, I'm so sorry, Don't worry, I know how you feel, You should ...) and things you should say (Congratulations, I am here for you, Lots of positive reinforcement, We will walk with you on your new journey, silence – sometimes say nothing at all)*
- *Built rapport (common ground, mirroring, ego suspension, talking slower, validate their thoughts and opinions, gift giving)*
- *Show empathy – fuel connections*
- *Keep support strong after the initial contact*

13. *Need a PAL? Successful Play-and-Learn (PAL) Groups for Families of Young Children -- Cyndi Johnson, B.S Psychology, M.Div. (Health Information Specialist, Family Voices Indiana) -- ppt available*

- *A P.A.L. (Play and Learn) session includes a play group; meet and greet; structured circle time; unstructured, supervised play time, chat and connect*
- *Would include infants and toddlers (0-3) with Ds, possibly an older group with preschoolers (3 – K), parents or caregivers, possibly siblings*
- *Benefits: parents feel supported by DSA, giving a sense of commitment early in parenting journey; may lead to parental engagement/involvement in DSA; opportunity for "mini" topical training; builds relationships; parents connect with and support each other; friendships and social skills for kids*
- *Speaker shared many details about how to set up and run the groups, get publicity, etc.*

NDSS BUDDY WALK CONFERENCE

AND

DOWN SYNDROME AFFILIATES IN ACTION LEADERSHIP CONFERENCE

Opening Session -- NDSS President and the National Buddy Walk Director

- Create a Buddy Walk Leaders Circle to recognize top local fundraisers
- Encourage self-advocates to bring their employers and wear their work uniforms
- Little Caesar's is a new National Partner! It is LC's goal to get involved in as many Buddy Walks as possible this year. I met the national coordinator for this effort, and he asked me to contact him directly. He will forge a relationship for us with local franchise owners.
- Miraflex frames will donate two pairs of frames to each Buddy Walk.
- Aardvark Straws is a new "swag" provider – they manufacture paper drinking straws with the Ds ribbon logo on them. (I have a sample they provided.)
- NDSS has a vendor that will create 18x24 signs for \$16.80. They suggested making them available for families to purchase, or providing them for families/teams at a certain fundraising amount (i.e., \$1000 raised)
- They discussed a new vendor for third-party fundraising for teams – Furnace Hills coffee creates "Buddy Walk Coffee". The purchase price of \$14/bag would include a \$1 donation to an orphanage in Ukraine, and a \$6 donation to CIDSO.
- They highlighted the ICanShine program, which provides recreational programs for individuals with disabilities, including iCanBike, iCanSwim, and iCanDance. Each one is a 5-day program (M-F) that comes to your community.
- Imagination Movers will record PSAs for the Buddy Walk.
- JK Custom Marketing has special pricing for medals/plaques/promo items. They are offering medals at an intro price of \$3 per medal with no minimum, and full-color plaques for \$18.
- Specs4Us will send pamphlets for tables.
- Strider Bikes will donate a bike for us. For a fee, we can set up an Adventure Zone with Strider Bikes.
- Woodbine House will donate a book about Ds for our walk. We can request materials for a table.

Adding a 3rd Party Fundraising Event into Team Fundraising Activities – John Gubser and Tony Thornberry (father and grandfather of a boy with Ds)

- The speakers have incorporated significant third party activities into their team fundraising, to the point that they raised over \$30,000 last year. They approached a restaurant in their area to donate a percentage of their lunch and dinner proceeds for their Buddy Walk team and raised \$800. They recruited people to bag groceries at a self-bag local store, and customers donated for their team – raised \$500.
- Their most lucrative effort is a Festivity Day they hold at a family member's farm on the second Sunday in August. The event includes raffles, auctions, door prizes, food, drinks, and games. They use the tax ID number for their Buddy Walk for all donations. Having the event on private property eliminates the need to get a gaming license. They spend a lot of time covering the details on how they hold this event.

Incorporating a 5K Into Your Buddy Walk – Bill Lawfield, Co-President, DS Association of Roanoke

- *Contact a local running club for a meeting/advice; especially organizations that have one every year. Ask organizers for a copy of their plans.*
- *Contact a running store.*
- *Pick a date and plan the event. Don't try to work around anything except very large events.*
- *Start small with a 3-5 year plan.*
- *Engage businesses for sponsorships at different levels.*
- *Perhaps a festival afterward?*
- *On the Friday night before the event, DSAR has had a great deal of success with a sponsor reception, recognizing sponsor levels. \$100 sponsorship = 2 tickets; \$1000 = table for 8. \$500 = 4 seats. If you aren't a sponsor, you can buy a ticket for \$100. Lawfield recommends investing in this – their sponsors love it. This event includes a presentation, meal, and dessert.*
- *Consider tying another group in with yours and sharing the revenue*
- *Don't judge the success of the event by the money raised.*
- *He believes that you limit fundraising by charging for participation in the event. Recommends taking a leap of faith and dropping the registration fee.*
- *Have the 5K timed – runners want an official time. Have awards and medals for different top division finishers. You don't need chips unless the run is very large.*
- *Bibs can be donated. Google: free running bib. The Running Store is a good resource.*
- *Some areas have a 5K Coalition – you can pay them to run the actual event. You seek the sponsors, get the t-shirts, etc.*
- *You need to check on appropriate insurance coverage.*
- *Have a Plan B in case things change.*
- *Promotion is key: flyers, online and paper registrations, QR codes, websites, other 5Ks, clubflyers.com*
- *VOLUNTEERS: set up, packet pick up, registrations, on the course, event tear down*
- *Bathrooms are needed – fixed or rented*
- *Food and beverage donations: fruit, water, bagels*
- *First responders are needed (off duty officers, EMTs)*
- *Emcee. Possibly a local radio host.*
- *Activities for families and children*
- *Tie in PSAs and local media*
- *Could use a high school track for the walk and 5K, possibly a cross-country track. Have your run end right before your BW begins.*
- *Think about what you want to have happen before and after the event. Color guard? National anthem?*
- *If you're only doing this for money raised, you might not want to do it. More effective for spreading awareness and promoting your mission.*
- *If you can manage to not charge for participating in your BW or run, you might be able to get the sponsors to pay for the event. But participants should still get a shirt.*
- *WalMart is a good source of volunteers. They can also give you money in a WalMart grant.*
- *Makes a good service project for fraternities/sororities.*

- *Your local water authority might be able to donate bottled water.*
- *Consider: renting cones/barricades if you're in an open/public area; are assembly permits needed?; marked clothing for volunteers/staff; communication devices for directors; 5K notifications prior to the event for any closures (residents, businesses on the route); plan for race day registrations; plan for awards after the event; how are you going to communicate the BW mission?; is advocacy going to be a part of your walk/run?*
- *Something is needed for people to do following the event while times/places are calculated – plan on about ½ hour. Awards for top finisher for each group.*
- *Sometimes you can have your local YMCA donate the use of their bounce house.*

Lightning Round

Topics were all over the board:

- *To charge a registration fee or not?? Most organizers said no. Believes that it generates higher donations. Consider the cost of the t-shirts to be just a cost of doing business. Have sponsors cover that cost?*
- *Planning a walk at the local zoo. Set timing so that the walk happens before the zoo opens for the day. Then families can choose to stay once it opens. 7:00 registration, 9:00 walk, 10:00 zoo opens.*
- *Having the walk at the county fairgrounds.*
- *The night before the walk, consider having a self advocate party/dance. This has worked well for some at a dance studio with multiple rooms. Offer karaoke, a movie, non-alcoholic theme drinks, a quiet room, a dancing room, etc.*
- *A VIP tent on the day of the walk for self-advocates only. Ages 16+, "Club Bud," DJ/karaoke, pizza/chips/cupcakes. Some have this only during a picnic after the walk wraps up.*
- *Use social media to run contests. For example, secure a matching donation: "For every donation made during the next 24 (or 48) hours, there will be a match up to a maximum of \$500"; or, any team raising \$100 this week is entered in a drawing for X*
- *Automatically set up your Twitter feed to tweet donations when they are received*
- *Consider running FB or twitter ads to increase the number of hits and donations*
- *Fundraising: online auction, use your t-shirts (any donations made today, this week, whatever, will get a free t-shirt)*
- *Hire a college student – for the 48 hours leading up to the walk and during the walk, posting, sharing, tagging, etc. to raise interest*
- *Connect with people on social media (famous people/celebrities)*

Online & On Fire – How to Supercharge and Streamline Your Online Presence – Jay Wilkinson, firespring.org -- print materials available

5 Elements of a Powerful and Engaging Website

- *Structure.* Users should be able to navigate it intuitively. 3-5 major sections; 8 max. Search tool Site map at the foot of the page. Key-word rich to help search engine optimization. Get anywhere on the site in 3 clicks or less.
- *Design.* Tell the story of the organization using photos and headlines.
- *Content.* The info we make available on our website – critically important. Deep and diverse content with all info someone might be looking for. Contextually relevant to all visitors. Content management system – should be able to add info without going to someone else to do it, using a simple drop and drag. This should be available to at least 3 people in the organization.
- *Functionality.* Tools built in to make it possible for constituents to connect with us. Volunteer, programs, event calendar, online registration (#1 request of users), online donations, news sign-up, connect. Online registration should NOT be a link to a PDF for users to print and send in.
- *Vitality.* The perception of freshness of content. Formula: dated content on the front page (headline w/ date) + post at least every 7 days + show 3 occurrences. Tells people the site is always up to date. Brings at least a 20% increase in repeat visitors. Easy way to do this – go spend time at quotegarden.com. Find 52 thoughts that go with your mission. Post 1 per week. Add graphics. Blog AND be a thought leader.

Convert supporters with powerful landing pages. Per Wilkinson, this is the most important thing you can do with your site.

- *What is a landing page?* The first page a visitor to your site sees. Typically, it causes 1 of 5 actions: Get a visitor to click (go to another page on your site or someone else's); get a visitor to give (money or time); get a visitor to give permission for your to follow up (by email, phone, etc.); get a visitor to tell a friend; get a visitor to learn.
- *Wilkinson provided an example of the perfect landing page* – should include an engaging, contextual headline; powerful image or video; limited navigation; a clear call to action

The power of landing pages

- *Site visitors who enter through a landing page will increase conversions 10 times over visitors who start on a homepage* – this means they are 10 times more likely to take action.
- *Your site should have a minimum of 5 landing pages.*

Search Engine Optimization – 6 Fundamentals for SEO Success

- *Keyword Research.* Keywords should focus on the name, mission, and location of your organization and the action you would like the visitor to take. Google has a free keyword planner tool. We can sign up for a google grant to get ads to pop up under certain keyword searches.
- *Website Optimization.* Key words in the text of the site. Don't overuse flash and animated GIFs (they aren't searchable). Limit search engine title tags to <70 characters and < 3 keywords. Name your images. Include a sitemap or footer map. Any navigation links should have keywords, not "click here."
- *Link Building.* Getting other websites to link to yours. The ABCs of Link Building: Anchor text matters; Be diverse with your links; Context over quality. Provided a list of possible links to boost rankings.

- *Fresh content. Select a content team and have a content strategy.*
- *Landing pages. Send users here instead of the main page.*
- *Analytics. How many people are clicking? How many take action? There are a number of tools to help answer these questions.*

Thought Leadership

- *One whose views on a subject are taken to be authoritative and influential.*
- *3 Keys to Becoming a Thought Leader: Commit to creating and posting great content (add value); Be the established expert; Inspire action.*

Blogging Strategies

- *Why should nonprofits blog? So you can tell your entire story (not just one chapter); to establish yourself and/or your organization as the authority; to get your message in front of more people; to get more web traffic.*
- *7 Components of the Best Nonprofit Blogs: Tell a great story; Encourage reader participation; Express gratitude; Go (ever)green with content that lasts; Well-edited; To the point; Produced by a team.*
- *Who should blog? People who are naturally wired to write.*
- *6 Steps to getting started with a team blog: Select your blogging team; meet and discuss the blog's theme and mission; establish expectations and assign roles brainstorm topics; divide and conquer; meet 1x/quarter or month and repeat steps 4 & 5*
- *3 content tips to optimize effectiveness: Diversify your content (2 out of every 5 posts should be evergreen; 1 out of every 5 posts should be an impact story); don't use ghost writers; give credit where credit is due (cite your sources)*
- *4 ways to promote your blog: partner with other bloggers; publicize your blog on social media; pay to promote on social media (twitter ad, boost post on FB); increase your blog's search engine optimization*
- *Measure your blog's performance*

Social Media for Nonprofits

- *Pinterest*
- *Instagram*
- *Facebook (91% of local searchers use FB to find local organizations online; 68% of people take time to learn about a charity if a friend posts about it)*
- *Twitter*
- *LinkedIn (most important: set up a "company" page for your nonprofit, and individuals should be set up on LinkedIn)*

5 Tips for Optimizing Your Social Presence

- *Use great content – 80% about your org and constituents (mission-specific); 20% community/quotes/etc.; photos garner 53% more likes, 104% more comments*

- Engage – questions posts receive 100% more engagement than statements; 55% of those who engage are inspired to connect
- Know your voice – determine your brand’s voice and tone, and directly convey it on social media
- Be transparent – develop a personal relationship between the organization and the audience. To earn trust, respond quickly to positive and negative feedback, and be proactive.
- Be consistent – Posting consistently is key. Create a calendar to help post consistently. This can be done in 15 minutes a day or less.

An Unprecedented and Exciting Down Syndrome Research Discovery Engine – The Crnic Institute Human Trisome Project – Keith Smith, Senior Professional Research Assistant

- Research drives the quality of medical care for individuals with Ds
- Follow the Global Down Syndrome Foundation on FB, Twitter, and Instagram
- In just the short time since they began mapping the bio-base, they discovered that, for all individuals with Ds whose samples they examined, the interferon pathways are open 24/7, from birth to death. I understand that the interferon pathways are usually opened in response to a threat from a virus. The researchers did not know the significance of this finding at this time, but the fact that there was something this clear that is connected to the extra copy of T21, especially found at the very beginning of their research, indicates that there is much more to be discovered and researched.
- The Crnic Institute is seeking individuals to provide biological samples and health information to answer specific research questions. They believe that this project will significantly increase the speed of Ds research and the understanding of associated medical conditions such as leukemia and Alzheimer’s disease.
- Who can participate? Anyone who is 6 mos. – 89 years old who (1) has Ds of any type; (2) has a family member with Ds but does not him/herself have Ds; (3) Does not have Ds and does not have a family member with Ds (the “control” group). The participation includes a single blood draw, a mouth swab, and allowing researchers to look at health information. Optional: provide a stool sample and take part in the study for a longer time frame. This takes place in Denver, CO. Some compensation is provided.

Online Tools that Help Nonprofits Learn, Listen & Engage – Jay Wilkinson

5 Elements of a Powerfully Engaged Website

- Structure – built and organized to find your way around when you get there
- Design – telling the story of your nonprofit through images and headlines
- Content – deep, diverse content so people find things engaging, meaningful, and of value. Should involve a Content Management System, such that there are a minimum of 3 people who can update website content in a manner that is point and click easy
- Functionality – things that make it easy for constituents to engage with our organization. Online registration is the #1 thing constituents want.
- Vitality – the perception of the freshness of content. Post dated content at least every 7 days.

Firespring has a free, online webinar called [How to Captivate and Engage Constituents with Your Website](#). Also see [The Power of Blogging and Thought Leadership for Nonprofits](#), and [Social Media 101 for Nonprofits](#)

5 Online Tools that will help you to be productive and build an audience

- *1Password – Manage all your passwords in one secure place*
- *Doodle – Scheduling with 3 or more people*
- *Springboard – managing website content (add landing page in proper format or any other page)*
- *Dropbox – makes it possible to keep all “stuff” in the cloud. Paid version has enough space for photos, etc. 30% discount through nonprofit. Only back up data.*
- *Evernote – Filing cabinets of hard drive in the sky. Keep track of things more smoothly. Free version is very helpful.*
- *Bonus: Picmonkey – design text overlay in photos. The free version is great.*

Listening Tools

- *Google Alerts – type a word or phrase to seek and find, discover when and where something was sent*
- *Mention.com*
- *Twitter.com/search*
- *Feedly.com – personalized magazine created for you – can add whatever features you want. The free version is good.*
- *Tootsuite.com – this is your dashboard. Allows you to see and manage all things going on in your world in one place. You don’t have to log in to each place separately – all in one place.*
- *Tweetdeck – owned by and focused on twitter*
- *Bufferapp.com – this is where you plan and post what content you are going to share. Can post all places from one dashboard. Can see optimal times to post based on their research. Can put items in a queue. Lets you know if there are comments, and you can engage from that platform. Free for one account per platform.*

To get started, spend 3-6 hours one time:

- *Set up your personal FB page*
- *Set up the FB page for your nonprofit (or ask for admin access)*
- *Set up twitter*
- *Sign up for 1password and use it*
- *Sign up for free Evernote and try it*
- *Set up your free Dropbox*
- *Set up Google Alerts to track the name of your nonprofit*
- *Set up feedly*
- *Set up bufferapp*

Spend no more than 15 min/day on social media. Use a content management system on your website. Keep learning – check out [nonprofithub.org](#) and [firespring.org](#) for free information.

Notes from Leaders' Circle – Support Staff and Committee Members

- BuddyUp Tennis – meets 1x/week for 10 weeks, ages 8+. Tennis teams volunteer, cost per family \$130.
- iCanShine camps
- When providing Medical or New Parent Outreach, provide materials that are evidence-based, well-rounded, and informative.
- Suggested creating a physician support folder with information about delivering a diagnosis
- There are several different types of informational support you can provide: prenatal, postnatal, physician support, nurses/office support
- You can include a referral sheet in the packet, with a place to indicate whether the parent wants to be contacted or not
- This is a very grant-friendly program!
- They recommend creating a magnet that providers, hospitals, social workers, etc. can put on a filing cabinet or similar, including the name of the org and a phone number
- Consider recruiting a Ds liaison at each hospital to be able to keep the packets
- In one org, the adult self-advocates made tie blankets and wrote notes to the new families (good adult programming); they also had bibs made with their logo
- 1x/month topic nights
- DADS group – Dads Appreciating Down Syndrome
- General Education Conference – covers PK-12 issues, disability neutral; inclusion, IEP, behavior
- Life in the Community Conference – put on in conjunction with ARC and Autism Society; focused on post-education life; adults with disability
- The Learning Program – offered by the Down Syndrome Foundation of Orange County. Parent classes and child classes. \$2K for Level 1, \$300 per family, pay teachers
- Quarterly Education Series for ages 0-5
- Adult Skill Training – public speaking, cooking
- Summer Employment Academy – paid school personnel to teach soft skills; identified businesses for job shadowing
- Seek out places that have Speaker's Bureaus. ABLE Act speaker.
- SmartStart – Kansas City Down Syndrome Guild. Kindergarten readiness program; parent-only program; behavioral topics; communication/school relationships; IEP. After each session, "homework"/things to try
- Look into having Home Depot come to Buddy Walk

Reach More New and Expectant Parents: Create a Customized Medical Outreach Plan! - Heather Bradley (DSDN), Stephanie Meredith (Medical Outreach Director, University of Kentucky), Sarah Cullen (Family Support Director, Massachusetts Down Syndrome Congress) -- ppt available

- MDSC Parent First Call program is a great model.
- Some states have a Trisomy Awareness Act that mandates certain information to be provided.

- AUCD.org
- Downsyndromediagnosis.org
- Lettercase.org – provides materials for medical professionals. Deliver to dr offices – for parents at the point of diagnosis. Pre-testing resources. Reviewed by national medical and disability advocacy organizations. ACOG, National Genetic Counseling Society counselors. Often included in medical guidelines. Available in 8 different translations.
- Pre-testing – overview of tests and their accuracy: cfDNA, cell-free DNA testing, NIPS, NIPT. Shows photos with different conditions.
- *Delivering a Diagnosis* – dealing with a range of conditions. Endorsed by scholars and physicians as “most balanced.” Makes us more valuable to physicians.
- Brightertomorrow.org – no more family support section
- Brighter-tomorrow.org – primarily a resource for clinicians. ACOG/ACMG/NSGC guidelines
- Downsyndromepregnancy.org – diagnosis to delivery materials. *Your Loved One is Having a Baby with Down Syndrome. Welcoming a Down Syndrome Diagnosis (post-natal)*
- Cited in multiple medical journals.
- Make sure that materials visually represent the populations you serve. Have multiple translations available. Be aware of the populations in your community. Materials that are accessible via many medias – can it condense to be readable on a phone, for example.
- Be aware of the need for information for pre-natal, pre-decision families.
- An opportunity to connect with a trained parent mentor.
- *Prenatal Get Togethers* – timing is dependent on the number of expectant parents. Targeted for third trimester. Genetic counselor and first call parents with their little ones.
- Genetic counselor collaborates – a paid consultant
- *First Call training* is 5.5 hours. Attends prenatal socials. Confidential support for new and expectant parents, first call parent mentors. Self-care workshop for support group leader retreat.
- *New Family socials* every other month. Include grandparents, siblings. Very informal.
- *Quarterly New Family workshops* – poss topics: baby massage, sign language, financial planning, state benefits.
- *DADS – Dads Appreciating Down Syndrome*
- *Hospital Care and Support – Heartbeats for Ds* (moms with heart kids); complex medical needs; welcome out of town visitors; hospital visits and care packages
- *Complex Needs Group* – families self-identify (autism, medically fragile, etc.) Quarterly meeting – autism connection, self-care, state resources/services, education/therapies/behavior
- *Down Syndrome Autism Connection (DSAC) FB group*
- *Cultural Diversity Task Force* – reach out to existing cultural groups that already support a range of disabilities
- *Cultural Diversity Group* – food and music, potluck dinners, diversity breakfast at their annual conference
- *Spanish Group* – Spanish speaking families with kids 0-10; interpreter; topics: speech, PT/OT, education
- *African-American Ds Families* – FB group
- *Collaborate and build relationships* – P2P (Parent to Parent program); AUCD.org

- *Identify barriers to participation – transportation, language, financial, cultural*
- *Build trust, respect, credibility, and professional relationships between medical providers and the Ds community*
- *Drop off First Call brochures/magnets in person*
- *Formal presentations – medical and scientific advisory committee*
- *Host a symposium*
- *DS 101 or Lunch and Learn*
- *Medical Schools*
- *Genetic counseling programs*
- *Connect – community health centers, OB/GYNs, perinatologists/neonatologists, social workers*
- *Use state birth statistics to focus efforts on high birth hospitals*
- *Develop/strengthen your First Call team – language, geography, medical challenges, cultural, religion*
- *Targeting underserved populations for grant initiatives*
- *HIPAA fax release – basket delivered? Mailed? Want to be on mailing list? Call within 24 hours?*
- *Hospital social workers might keep your materials in their office space.*

Raising Major Gifts in a Small Nonprofit - Betsy Wilson (Director of Major Gifts and Planned Giving, Community First Solutions) – ppt available

What is a major gift?

- *Can be annual or occasional*
- *Larger than your organizations “norm”*
- *Must define the \$ amount for your organization*
- *Smaller donor/prospect pool*
- *Lots of face time*
- *Requires lead time to see results*

Benefit

- *Most efficient return on time, energy, and investment*
- *Secures the future*
- *Sustainable cash flow*
- *Develops relationships with supporters*
- *Can lead to planned and estate gifts*

www.qailperry.com

Where to start? Define what is considered a major gift at your organization.

Identify and qualify

- *Who are your top prospects and where do you find them? Start with your database (razor's edge; donor perfect; dbs)*
- *Consecutive giving is a major indicator*
- *List should be pretty small. 20?*
- *If they aren't moving up, they need to come off the list. Research individuals on google.*

Annual reports list donors. Get an idea of where else your top prospects are giving.

Ask board members for info on some prospects.

Qualify – look for connection and capacity to give. Need to build a relationship before asking.

Build a relationship with each donor on your prospect list

- *Invite to events*
- *“Ask for advice” meeting*
- *Involve in volunteer work or committee*
- *Help them feel like a valued member of your organization*
- *Find out what the donor is passionate about*
- *Moves management: attendee to committee member to board member to donor to major gift donor*

The Ask

- *What are you specifically asking to fund?*
- *The right person, asking the right person, at the right time, for the right amount, for the right project*
- *Quiet, comfortable place*
- *Prep for the visit: if another person is there, script with them so you aren't talking over each other and there aren't awkward silences. Warm up. Transition to present the opportunity in a way that is clear, concise, and compelling.*
- *Once it's out there, you have to “zip it”*

Do they want to be recognized? How do they want to communicate?

Send advocates out for a special thank you visit.

There will be no. Even if there's a no, the stewardship and thanking stays the same.

Ideas: note, call, letter, email, hug, handshake, thank you videos, notes from clients, social media shout-outs, special holiday treats.

Community Outreach: How to Open Doors and Educate Others About Down Syndrome -- Christine Newlon (Public Speaker and Outreach Specialist, NADS) – ppt available

Know your DSA's purpose -- Serving individuals with Ds and their families – basic information, programming, educational programs, family support

Identify community outreach goals – serving others in the Ds community; increasing the number of individuals served; expanding to other diagnoses

Educating about Ds: community awareness, inclusivity, medical personnel

Networking: recruiting volunteers, fundraising, partnerships

Starting the conversation

- *Identifying the organization's needs*
- *Reach out to other local support groups – who do they serve? How do they get clients?*
- *Join other service organizations: Kiwanis, Lions Club, Chamber of Commerce*
- *Avoid overlapping services*

Target groups: Hospitals

- *Our goals: up to date information to them; connect with families*
- *Their goals: Hospital personnel education; improve physician/patient relations; increased services*
- *Target audience: nurses; doctors; support personnel; program directors*
- *Hospital contacts: Director of Nursing; social work department; Chief of Staff/hospital board*
- *They want to know what to say to patient*
- *We want them not to say "X"*
- *We want them to say: Congratulate the family – blessing of a baby; How beautiful the baby is; They are babies first; Their reaction is normal – you are not a bad person; The perfect thing to say may be nothing; All children are journeys; Just love the baby*
- *Advice for the dr: don't give your nonverbal cues away in the delivery room. Unless the child needs to be rushed to NICU, let the family fall in love with the baby. Don't ask the mom: did you have prenatal testing? Don't give a laundry list of all possible problems.*
- *Reassure the provider that they aren't expected to have all the answers, but know where the brochures are*

Target group: schools

- *Our goals: increase awareness; improve inclusive practices; decrease bullying; volunteer/fundraiser/special event*
- *Discuss: facts about Ds; real world applications; volunteer opportunities*
- *Contacts: teachers of health/parenting classes, special ed programs; club supervisors; coaches; counselors; PTO*
- *Penny presentation: Each person gets a penny. Turn it heads up. What do you see? What does it feel like? How many know someone with Ds? When you see someone with Ds, how do you know they have it? (Nothing you say will offend me.) Flip the coin over. What is on the other side? Low muscle tone has a huge impact: trunk, diaphragm, chest, cheeks, neck, lips, tongue,*

and breath. Therapy. Hyperflexibility. Want students to see that Ds is not scary. Encourage them to be more patient. Ok to ask more if they don't understand. Some individual have touch, light, or sound sensitivities. Sonic boom in their head all the time. Bump someone and they overreact? May be sensitive to touch. It's ok – just know that and don't do it again. Could be someone who is beaten or harassed. Not all individuals with Ds have sensitivities; not all people with sensitivities have Ds. What is the value of that coin? They are all the same, even if they don't look the same. What is the value of each person?

- *Focus on similarities*
- *Use person-first language*
- *Use of the R-word and variations*
- *Include volunteer opportunities*
- *Finish with Just Like You video from the DSO of Kansas City*
- *High School extra curricular activities (Key Club, Honor Societies, Clubs (art, computer, music, dance, theatre), sports – volunteer, but have limited time*

Coordinating a Sports Day

- *Contact the coach in winter/spring. Explain the important issues: muscle tone, balance, speaking clearly, demonstrating. Pair one player with each child.*
- *Set a date/time. Put on the athletic schedule.*
- *Send a save the date to clients (all children under 18).*
- *6-8 weeks before: Contact the coach. Begin training. RSVPs.*
- *4 weeks prior: go into details; athletes design activities; get supplies and equipment; snacks and drinks; committees (make signs, plan games)*
- *Committee brainstorms/get started. No coach/parent input. Include area for younger kids as well as quiet space. They track down the equipment they need for the activities they plan.*
- *Taco Tuesday. Sign making, final plays for equipment.*
- *Let each player know who their buddy will be. Care with each child's name, age, issues to be aware of. Some kids need two buddies.*

Meet A New Family Where They Are At (Prenatal or Post-Birth) - Jena Wells (Early Matters Coordinator, Down Syndrome Association of Greater Cincinnati) -- ppt available

Early Matters covers diagnosis through age 5 (school age)

Seven Stages of Grief

- *Shock/Denial/Numbness – “This can't be happening. Wake me up from this nightmare.”*
- *Pain/Guilt – life feels chaotic and scary*
- *Anger/Bargaining – unwarranted blame*
- *Depression/Reflection/Loneliness – realize full magnitude of loss, isolate yourself, emptiness, despair*
- *The Upward Turn – physical symptoms lessen, start to adjust life*

- *Reconstruction/Working Through* – become more functional and seek realistic solutions to problems
- *Acceptance/Hope* – Plan for the future, anticipate good times (this does not mean instant happiness)

Things not to say:

- *At least ...*
- *It's God's will ...*
- *I'm so sorry ...*
- *Don't worry ...*
- *I know how you feel.*
- *You should ...*

Talk about similarities, but otherwise no need to discuss everything (diagnosis stories, etc.)

What to say:

- *Congratulations*
- *I am here for you*
- *Lots of positive reinforcement*
- *We will walk together on your new journey*
- *Silence – say nothing at all*

People like gifts! Shows that you care about them. Follow up with little gifts. Keep support strong after initial contact.

Built rapport

- *Find common ground*
- *Use mirroring*
- *Ego suspension*
- *Talking slower – gives more credibility*
- *Gift giving*
- *Forget preconceptions and ideas about what I think I know about them*
- *Create similarities*
- *Treat others as you would want to be treated*
- *Flip your perspective*
- *Focus on small things – important to know their names (families and babies)*
- *Appreciate your own life so you can appreciate others'*

Empathy fuels connection

- *Perspective-taking*
- *Staying out of judgment*
- *Recognizing emotion in other people*

- *Sharing that*
- *Connecting with something in yourself that knows that feeling*
- *“I don’t even know what so say right now. I’m just glad you told me.”*

Keep support strong

- *Follow up with email and/or card in the next few days*
- *Send out additional resources/upcoming events that were discussed*
- *Connect family with mentors/support groups/FB groups*
- *Get them in your database to receive future communication*
- *Reach out again in 3 mos and 6 mos*

Need a PAL? Successful Play-and-Learn (PAL) Groups for Families of Young Children -- Cyndi Johnson, B.S Psychology, M.Div. (Health Information Specialist, Family Voices Indiana) -- ppt available

PAL Session

- *Play group – how kids learn*
- *Meet and greet*
- *Structured circle time*
- *Unstructured, supervised play time*
- *Chat and connect*

Who?

- *Infants and toddlers (0-3) with Ds*
- *Older groups might include preschoolers (3 – K) with Ds*
- *Parents or caregivers*
- *Siblings?*

Why?

- *Simple, inexpensive, effective, low-barrier program*
- *Parents feel supported by your DSA, giving a sense of commitment early in parenting journey*
- *May lead to parental engagement/involvement in your DSA*
- *Opportunity for bite-size topical training on important issues (accessing services, legislative advocacy, future planning)*
- *What is going on – in a nutshell*

Benefits to families

- *Relationships*
- *Parents connect and support*

- *Friendships and social skills for kids*
- *Kids and parents “grow up together”*
- *Parents learn time-saving ways to incorporate skill-based play into busy days*

Where?

- *Accessible location and space*
- *Ample parking*
- *Completely baby proofed*
- *Sensory area a bonus*
- *Church nursery, preschools, libraries, therapy clinics*

What happens – 1.5 hours (book longer for conversations, etc.)

- *20 min: settle in, accommodate late arrivals, get snacks*
- *10 min: formal welcome infomercial*
- *30 min: structured circle time – only rule: little ones enjoy the space, wherever it is, be safe, and enjoy whatever your little one needs*
- *30 min: unstructured play time. Children play while parents chat*

When?

- *Frequency: monthly? Quarterly? (this is a good start)*
- *Special sessions? Holiday parties, summer picnics, fall hikes*
- *Day of week? Weekends?*
- *Doodle poll for best day*
- *3 year cycle of sessions to avoid duplication and sustain interest*

Google “care seat safety Down syndrome Riley” – great resource for safety issues

Who do you need?

- *Coordinator*
- *Facilitator*
- *Circle time leader*

Possible circle time leaders/topics

- *Therapists: SLP (feeding, mouth sensitivities), OT (sensory issues), PT, music, recreational, behavioral*
- *Positive behavior/discipline*
- *Educators: developmental preschool directors, SpEd teachers, Head Start inclusion specialists (they have a quote to meet – meeting the needs of kids w/ special needs)*
- *Others: literacy specialists (local children’s librarian), sign language instructors, dance instructors, infant massage, therapy dog trainers, car seat safety inspectors*
- *Potty training – circle time with kids on potties*
- *Healthy sleep habits*

- *Dietician/nutritionist*
- *Medical guidelines (Ds clinic, pediatrician or nurse practitioner, brings stethoscopes and supplies, kids bring teddy bears for check ups)*
- *Dental w/ speech therapy*

Need screened volunteers for play time. One DSAIA membership benefit is discounted background checks from one of its preferred vendors. No screening required for kids under 18. Check with the OT club at your local university.

Thank people 7 times

Publicity

- *Website*
- *Social media*
- *Newsletters*
- *New parent packets*
- *Fliers or swag @ Buddy Walk*
- *Parent testimonials*
- *DADS correspondence*
- *First birthday gifts/cards (BOBUX – shoes with an invitation to save the date for the BW “These shoes are made for walkin’”, book, card signed by teens and self-advocates*

Tips for Success

- *Have parents register. Can be a simple evite*
- *Take homes, make and takes are a big hit, or have circle leader purchase a bag of learning goodies for families*
- *Refreshments are nice. Breakfast?*
- *If you have a larger group, consider separate sessions by age group (0-18 m, 18-36m, etc.)*
- *Develop a logo or just use the one speaker has made*

Cost containment

- *Therapists may volunteer time, or may offer an honorarium*
- *Church nurseries*
- *Local libraries may lead circle time and provide free books*
- *Rotation sign up for parents to bring snacks*
- *Consider having a suggested donation per session during registration*
- *Write a mini-grant*

Pilot PAL session

Plan PAL sessions for remaining ¼ of 2017