

IDEAS TO RAISE AWARENESS ABOUT RETT SYNDROME

OUR GOAL:

We want everyone in the world to know what Rett syndrome is and why it's important to fund and find treatments and a cure.

This is going to sound so elementary, but I want you think about this for a MOMENT...

If our goal is to have the whole world learn about Rett syndrome, then we have to ask ourselves how can we get the message about Rett syndrome into the hearts and minds of as many people as possible ? Right? And since this coming month of OCTOBER is Rett Syndrome Awareness Month, we want to reach as many people as we can ... so ... this begs the question where in our lives can we reach large groups of people?

Family and Friends
Work
Schools
Churches
Civic and Social Groups
Sporting Events
Movies/Theater/Music Events
Busy Intersections
Radio
TV
Newspapers
Mail
Internet
Social Media
(Facebook, Twitter, YouTube, Pinterest, blogs, and other electronic media outlets)
News and Blogs
Emails
Instant Messages

THE BIG MESSAGE HERE IS: GO TO WHERE THE LARGEST GROUPS OF PEOPLE ARE!

RETT SYNDROME MESSAGES

Clear and concise messages about Rett Syndrome and your loved one with Rett Syndrome.

Let's start with some basic advertising ... The 3:30:3 rule.

If you can grab someone's attention in...

3 seconds

You will earn...

30 seconds.

And if you captivate their attention in that time they'll give you up to...

3 minutes.

How you spend each of those valuable seconds and minutes is crucial.

So, what's your 3 second message?

Here are some ideas...

MY DAUGHTER HAS RETT SYNDROME AND I'M WORKING FOR A CURE

HELP ME SAVE MY DAUGHTER'S LIFE. LEARN ABOUT RETT SYNDROME.

WHAT'S RETT SYNDROME? MY DAUGHTER WANTS YOU TO KNOW.

THERE IS A CURE FOR RETT SYNDROME—HELP US GET IT A.S.A.P.

(Obviously change out daughter with granddaughter, niece, sister, friend . . . whatever the case may be).

You want something short and sweet and attention grabbing. The haiku. The headline. It's the first four notes of Beethoven's 5th Symphony. (da-da-da-daaaa).

BTW: Think visually. You can grab their attention with a photo or a graphic too.

Now you've earned 30 seconds of their time . . . how are you going to capitalize on their message?

Now you need a concise explanation of what Rett syndrome is so people can remember it.

My daughter _____ has Rett syndrome which is a devastating neurological disorder that primarily impacts girls and women. On the autism spectrum, from mild to most extreme, Rett syndrome is considered the most extreme. It's heartbreaking. But, the good news is researchers have proven Rett syndrome is REVERSIBLE, but we need the funds to turn this scientific fact into a living, real world reality. And we want to do this A.S.A.P.

[Add five seconds of a personalized message here.]

My daughter, _____, and I would love you to help us to tell others about Rett syndrome. Do you want to know how you can help?

Okay . . . now you've earned 3 minutes of their time. That could be three minutes of reading or conversation. In a focused three minutes you should be able to tell them a short, unforgettable **story** about your loved one and the efforts of organization's like the International Rett Syndrome Foundation to help families and fund researchers to find treatments and a cure.

Then give them something very specific to do:

Tell 10 people about Rett syndrome.
Tweet about it.
Write an article about it.
Go to your First Giving page and donate.
Volunteer at your upcoming fundraiser.
Etc.

The overall message should be about hope, love, and growing momentum. People want to root for winners. IRSF has a track record of success. We funded the gene discovery, the reversal studies, and now the first human drug trials . . . this is the right team to root for.

AWARENESS OPPORTUNITIES

Now we need to take those messages and get them out there.

We need to be shameless.

We want to customize these messages to each of the audiences.

Ask yourself . . . if I were in this group of people, what would appeal to me the most?

It will be different for different groups of people. Everyone has their combination lock to open up their hearts and minds and spirits.

So, if you're targeting large crowds of people in a football stadium a long paragraph won't help you. A bold letter, high-contrast sign with a concise message will. If there are TV cameras around you may want to add the link www.rettsyndrome.org to the bottom of your sign. Or #rettsyndrome

Most people won't remember the link, but they may remember Rett syndrome has a website and find it that way.

If you're speaking to a group of students . . . what would appeal to them the most?

If they're young. Maybe it's a picture they can color or a puzzle that has words about Rett syndrome in them. If they're older, maybe you want to create a contest where you give away tickets to an upcoming Justin Beiber concert (or whatever) to see who can IM the most people about your First Giving site for Rett syndrome.

Tailor the messages to your audience.

Five things to keep in mind:

1. Keep it short.
2. Make it personal.
3. Be passionate.
4. Focus on hope.
5. Give them something specific to do.

So . . . let's brainstorm real quickly about how you can reach these big groups of people.

AUDIENCE	IDEAS
Family, Friends, Neighbors	Personal call, letter, email, photos, party, fundraiser, lemonade stand, block party, BBQ cook-off, etc.
Work	Personal conversation, email, newsletter article, flier, party, fundraiser, sponsor the donuts for a month, moist towelleles in the bathrooms, etc., bring your loved one to work one day,
Schools	Visit classrooms, ask for full assemblies, handouts, activity pages, sponsor a party, sponsor a team, and so on.
Churches, Civic, and Social Groups	Ask for an opportunity to speak (if you're shy, get someone you know who isn't to do it for you), get in the newsletter, set up a booth outside, picnics, activities, etc.
Places of Business	Placards for restaurant tables, poster, fliers, specials on the menu,
Sporting Events	Signs, booths, cheerleaders (kids, moms, or even dads), sponsored tailgating, etc.
Movies/Theater/Music Events	Get permission to show a slide on the screen of the theater before the program, get an ad in the program, stand up with a sign just before, work the parking lot, get the musicians to mention it on stage, bring your daughter, have handouts.

Busy Intersections	Are you willing to beg for a cure? THOUSANDS of people pass the people with signs working major intersections everyday.
Radio, TV, Newspapers	Use IRSF's October Awareness materials to get the word out (Clint Black, Press Releases, etc.), ask to be interviewed about RS in October, Create a publicity stunt (stay in a tree for a month, wear a mouse costume for a month, ANYTHING that will attract attention for a sustained amount of time) and write a press release about a RS activity, write letters to editors, hold signs at TV events (NBC, ABC, FOX, CBS, etc.). Use the Governor Proclamations to get news stories.
Mail & emails	Write a personal, heartfelt letter, (get your kids to write it or daughter's friends, or any famous people you know) tell your story, illustrate it, make it unforgettable and send it to EVERYBODY.
Social Media (Facebook, Twitter, YouTube, Pinterest, blogs, and other electronic media outlets) and Instant Messages	Post or send a message EVERYDAY in October. Brainstorm 31 things you want the world to know about your daughter, her life, her capabilities, what her friends and family think of her, what you want them to know about Rett syndrome, and what they can do to help. Tweet, Facebook, blog, IM or email these messages EVERYDAY. Use photos and do it on Pinterest. 31 photos of my loved one with Rett syndrome. Beg everyone to pass these links on or at least LIKE them. Send 31 inspirational quotes in October. Make 31 mini-movies for YOU TUBE (or one really good one your send people to everyday for a month). Use classrooms or friends to do the same.
News and Blogs	Comment on news stories and blog entries for a month and relate them to Rett syndrome. For example there might be an article about Mars exploration and you can comment on why you love space exploration and