

January 25, 2012

## Alone we are rare... together we are strong.

It's not just the slogan for the global campaign marking **Rare Disease Awareness Day** on **February 29, 2012**. It's also the rallying cry for "**SOARING VOICES**" a grassroots effort by patients, friends, and families who meet the challenges of a rare disease diagnosis with grace, dignity, and a positive attitude.

**EURORDIS**, the European Organization for Rare Diseases, defines a disease or disorder as rare when it affects fewer than 500 in one million of population (Orphan Drug Regulation 141/2000). An ultra-rare designation is generally considered for rare diseases that affect fewer (sometimes far fewer) than 20 patients per one million of population. In the United States **NORD** (The National Organization for Rare Disorders) helps the nearly 30 million Americans with rare diseases through programs that empower, educate, and support patients and patient organizations, though estimates indicate perhaps there are 350 million people worldwide affected by rare diseases. Many rare disorders and diseases are severe, chronic and progressive, and have serious impact for not only the patient but also their whole family. Compounding the seriousness of rare diseases is a lack of scientific knowledge, issues with diagnosis, limited treatment options, and little opportunity to connect with other patient families who share the same diagnosis.

**Watch Tricky Britches** at performing their uplifting and original bluegrass song "A Rare One", and learn about opportunities for rare disease patients to gain information, inspiration, and support through the network of Rare Disease Patient Communities, a joint initiative of NORD and Eurordis. Amazingly about 1 in 10 people suffer with a diagnosis of a rare disease, but since so few individuals compose each of the approximately 7000 rare disease groups, we are largely an invisible and unseen patient population.

Join the discussion at [www.rarediseasecommunities.org](http://www.rarediseasecommunities.org) – if your particular rare disease is not currently represented, NORD and Eurordis will create a new patient community. A free global networking opportunity to gain information and support, these disease-specific communities include current research, conference details, and patient viewpoints offered within a moderated, reliable site with translation across 5 languages. Help give rare disease patients a voice – encourage us to gather in a visible community where we can share our stories, access information, and create a supportive community connected to research and hope for a brighter day. How?

**The SOARING VOICES project asks you to create a video clip or slideshow that informs, enlightens, and uplifts ...**showing the beauty in life and laughter. While patients with rare diseases don't live charmed lives, we can create 'charmed moments' to gather and be heard around the world – providing moments of grace and humor, while demonstrating the power of love and strength in our commitment to find solutions. **Make Rare Disease Day, Wednesday, February 29th shine** – submit your video or slideshow to NORD and Eurordis **for our global upload to YouTube to honor and give support to rare disease patients and their families.** The Soaring Voices project welcomes slideshows or videos from organizations, researchers, hospitals, service clubs, medical personnel, and other companies or groups that have an interest in rare disease issues.



Upload your video or slideshow to both the international Rare Disease Day site at <http://video.rarediseaseday.org/yourstory/video>, and our dedicated Soaring Voices channel at <http://www.youtube.com/user/aHUSrarediseaseday>. (See upload instructions on page 3.) There are also a variety of videos viewable at the [International RDD stream](#).

Rare disease patients often hear, “What can I do to help?” from friends and family members – usually we feel powerless and have no way to channel those kind intentions. Joining our voices removes rare disease patients from isolation, and their struggle to find meaning while feeling alone with a diagnosis of a rare disease. Instead, gathering together into a community gives patients a strong voice to express their point of view, allowing millions of rare disease patients to unite and connect with purpose.

Think of **ideas** that can illustrate the Rare Disease Day theme, “Alone we are Rare, Together we are Strong!” Plan your video or slideshow to express your feelings, share your story, support your friend/family/rare disease group, or highlight your work/volunteer effort/organization. Our Soaring Voices project is not a contest, nor does it have a bunch of guidelines to follow – just amaze us with your innovative approach to rare disease awareness that builds on these few components:

- **Keeping with the Rare Disease Day theme**, “Alone we are Rare, Together we are Strong!” illustrates that concept of moving from ‘isolation/aloneness’ to ‘community/connectedness’ throughout your project.
- **Please download Rare Disease Day graphics**, or our **Soaring Voices poster** and include it in your video or slideshow – or display these graphics during your filmed public performance piece. “A Rare One” by Tricky Britches is available for download at **CD Baby** (with an **instrumental version** as well). Song lyrics are available in **English, French, and Spanish**.
- Offer a strong message for rare disease awareness, with your original video or slideshow entry (5 minutes or less). Add info about your disease, group, company, or organization. Let your point of view shine through! Upload your video or slideshow to both the international Rare Disease Day site at <http://video.rarediseaseday.org/yourstory/video>, and our dedicated Soaring Voices channel at <http://www.youtube.com/user/aHUSrarediseaseday>. (See upload instructions on page 3.) A variety of videos viewable at the [International RDD stream](#).

**Be creative.** Add meaningful content with a positive twist. Together we’ll increase awareness of rare diseases across the world by creating innovative and positive messages about patients and families meeting challenges. Our voices will soar and offer hope - patients and their families can connect with the rare disease community network at [www.rarediseasecommunities.org](http://www.rarediseasecommunities.org), a linking hub of disease-specific information, and support. Our focus with Soaring Voices is to deliberately and joyfully choose to turn our faces to the sun – so shine your light and smooth the path for rare disease patients and their families with your participation.

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Sponsored by The Foundation for Children with Atypical HUS (co-founders Bill and Cheryl Biermann). Soaring Voices was created by **Linda Burke**, founder of [www.atypicalhus.org](http://www.atypicalhus.org).

We gratefully acknowledge the videographic talents of director/producer **Randy Visser**, Sue Raftice, and their crew. Thanks to Local Sprouts café in Portland, Maine for hosting the Tricky Britches video shoot, to Tim Tierney and “A Rare One” CD audio production staff at The Studio in Portland, Maine.



Our special thanks to **Tricky Britches** for their inspirational song, "A Rare One". 20% of the net proceeds from the \$1.29 purchase price of the CD Baby download or instrumental version of "A Rare One" by Tricky Britches goes to support patients with rare diseases through these **five organizations** (Status as 501(c)(3) charitable organizations): Songs of Love [www.songsoflove.org](http://www.songsoflove.org), the R.A.R.E. Project [www.RAREproject.org](http://www.RAREproject.org), Grahamtastics Organization [www.grahamtastic.org](http://www.grahamtastic.org), the Foundation for Children with Atypical HUS [www.atypicalhus.org](http://www.atypicalhus.org), and NORD and Eurordis patient programs through <http://www.rarediseasecommunities.org>.

Our appreciation to Steve Greene and **Alpha Marketing** for their continued efforts and support of [www.atypicalhus.org](http://www.atypicalhus.org) and rare disease families.

## Instructions on uploading videos to YouTube Channel.

1. Sign in to YouTube account by visiting <http://www.youtube.com>
2. In the top right hand corner of the page click 'Sign In'
3. Enter username: **aHUSrarediseaseday** and password: **Linda1234**
4. At the top of the page click 'Upload'
5. You will be prompted to upload a single file from your computer, upload multiple files, or record from webcam.
6. If you are uploading one file click 'Select Files From Your Computer'
7. YouTube accepts the following file types:
  - WebM files** - Vp8 video codec and Vorbis Audio codecs
  - MPEG4, 3GPP and MOV files** - Typically supporting h264, mpeg4 video codecs, and AAC audio codec
  - AVI** - Many cameras output this format - typically the video codec is MJPEG and audio is PCM
  - MPEGPS** - Typically supporting MPEG2 video codec and MP2 audio
  - WMV** - Windows Media Video
  - FLV** - Adobe-FLV1 video codec, MP3 audio
8. After selecting a file, you will be taken to a screen where you will be able to input the title of the video, write a description that will live below the video itself, as well as add tags, which are keywords separated by commas that will help allow people searching on YouTube to find your video. If I were uploading a video of a red Corvette driving down a country road I would use the tags Corvette, Red, Country Road, Fast, Car, Chevy; anything that would allow someone searching YouTube to view my movie. You will also have the option of choosing a thumbnail for your video that YouTube will generate for you based on frames taken from the video itself. You can also choose a category for your video to fall under, YouTube provides a variety to choose from.
9. When you are finished, click on the **aHUSrarediseaseday** button in the top right hand corner of the page. From the drop-down menu choose 'My Channel' to view videos, or 'Video Manager' to further edit the video you have uploaded.

