News About Trisomy – What’s New?

WHAT’S NEW notifications of FAMILY STORIES and NEWS EVENTS can be sent to your email inbox each time the page is updated. Click on the blue link to go to a service that will do this for you: https://www.followthatpage.com

ENTER https://trisomy.wpengine.com/?page_id=2889/ as the page to follow, and your email address. You will be notified by email whenever the page is updated. This service is available for any page on the website – only the “page_id” will change. Find the page_id number in the page’s URL.

Scroll down to see a list of recently added family stories and scroll down below those to see Trisomy News items!

11/26/2018 – Oscar’s Story (FT13)
11/26/2018 – Elisabeth’s Story (trisomy 13)
11/26/2018 – Olivia’s Story (trisomy 13) update

10/25/2018 – April’s Story (trisomy 18 and CDH)

09/08/18 – Aspen’s Story (trisomy 18)

08/03/2018 – Alissa’s (LeeLee) story (trisomy 18) update

06/25/2018 – Alishba’s Story (partial trisomy 13)
06/05/2018 – Olivia’s Story (trisomy 13)
05/12/2018 – Eden’s Story (mosaic trisomy 18) update

02/01/2018 – Elise’s Story (trisomy 18)

12/14/2017 – Amara’s Story (trisomy 18) update

11/14/2017 – Elijah’s Story (trisomy 18 and Klinefelter Syndrome)

11/03/2017 – Kimmie’s Story (trisomy 13 mosaic) update

10/16/2017 – Grace’s Story (trisomy 13/dandy-walker brain malformation)

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What’s New in our trisomy world?


♥ 8/6/2018  Child’s Trisomy Condition Spurs Medical Invention

♥ 7/26/2018  Zalyn has mosaic trisomy 18! Read about it here.

♥ 12/17/2017  Stanford Medicine News Center, 2017 Infants with the genetic disorders trisomy 13 or 18 are more likely to survive if they undergo heart surgery, a study from researchers at Stanford and the University of
Arkansas has found.


♥ 07/25/2017   High Point, NC, toddler with Trisomy 13 beating the odds (a video)

♥ 05/23/2017   A story in the Greenville, TN Sun about caring for Brilen who was born with trisomy 13, and his Maxim home health Nurse, Melissa Seal, LPN.

♥ 03/02/2017   Portraits by Dana have been added to the “Helpful Organizations” website page: “For the last 18 yrs I have specialized in gently-drawn pencil portraits for families who have suffered an early loss. Many thanks and blessings.” Website: https://www.portraitsbydana.com/ Facebook: https://www.facebook.com/portraitsbydana

♥ 02/28/2017   A link to information about Apnea has been added to the site and can be found at Resources>Helpful information. Pediatric Apnea – a Medscape overview.

♥ 02/17/2017   Doing the Right Thing: Raising money for SOFT: Ann Hameister organizes a bowling tournament to raise funds for SOFT.

♥ 11/10/2016   18 month-old with rare genetic condition survives against the odds. When Amy Strasburg gave birth to her baby girl, Avery, in February 2015, the joyous day had come after a “healthy, normal pregnancy.” But Amy and her husband, Andy, as well as Avery’s doctors, knew something was wrong.

♥ 9/30/2016   The latest issue of the American Journal of
Medical Genetics is dedicated to trisomy 18 and 13 conditions. Dr. John C. Carey, SOFT’s medical advisor, edits the journal, and the articles are available for reading. Click the link and the publisher’s website will open. Scroll down to select the article you want to read.

The cover photographs were taken by Rick Guidotti, famous photographer and founder of Positive Exposure, at the 2016 SOFT Conference in Tacoma, WA. The children have full trisomy 13 or 18 except for one girl with mosaic trisomy 13.

♥ 3/19/2016 Olivia Wilde Plays a Girl with Down Syndrome in eye-opening film

♥ 02/02/2016 Publication of data from a CombiMatrix study supporting the value of follow-up diagnostic testing to either confirm or rule out positive results for common chromosomal aneuploidies and microdeletion syndromes detected by non-invasive prenatal testing (NIPT).