

# Well Done, Ed Sheeran! Keep that Spotlight on Rare Disease



By *Jamie Wells, M.D.* — May 4, 2017



Credit: Shutterstock [1]

And, the award for promoting public health and being a patient advocate goes to... Ed Sheeran!

Two weeks in a row, the musician has not only created unforgettable moments for several children battling severe diseases and their families, but he has also utilized his social media and other platforms to showcase much needed attention on Batten Disease and Rett Syndrome.

Please do not underestimate the meaning of this spotlight. To the individuals directly involved. To those suffering in the shadows. To their loved ones. To the scientific and medical communities in search of a champion. Champions funnel resources to research-- our greatest route to effective therapies and cure. They also buoy spirits in times of immense suffering.

As part of [ACSH's #GetWells campaign](#) [2], our goal is to be a voice for those enduring devastating illnesses-- who especially feel like their disease is an invisible one. I extensively address this in my plea to Tinseltown, see [Dear Hollywood: Jack Black Shows How Health Outreach is More Than Environmental PSAs](#) [3].

Ed Sheeran appears to recognize the power of his influence. Today, it hit the news that he held a private concert for a fan who also is afflicted by Rett Syndrome-- a rare, neurodegenerative disorder. See video [here](#) [4] and [here](#) [5]. This was not a one off event. He originally met her while on a [prior hospital visit](#) [6]. At that meeting in 2016, it was [reported](#) [7] then 9 year-old Melody Driscoll spent 80% of her life in the hospital and had experienced over 40 surgeries. She cannot walk or talk. But, comprehends everything.

Rett Syndrome is a rare genetic condition that impairs neurological and developmental functioning.

It is progressive and almost exclusively affects girls. (1)

Last week, he brought joy to a family enduring unimaginable struggles with Batten Disease, having two children-- Ollie and Amelia-- directly impacted. As the mother of 6 year old Ollie Carroll described-- [in this published report](#) [8], the singer's gesture was touching and his voice pulled her son through "the hardest and darkest of times." At present, Ollie can no longer see, walk or talk, but when Sheeran entered the room and began speaking "Ollie's eyes lit up and a smile spread across his face. This image was priceless."

It was via social media that the Carroll family caught the singer's attention. To comprehend their challenges and the significance of this experience for Ollie and his loved ones, review the video of Ollie's disease progression and the family's postings in their own words [here](#) [9].

Batten Disease is a fatal, inherited nervous system disorder. There is no cure. (2)

It also appears he called and sang to a [young woman](#) [10] just before her death. She had [Cystic Fibrosis](#) [11]-- another rare, genetic disorder that prompts thick mucus to accumulate in the lungs, pancreas and other organs. These patients are routinely sickened by respiratory infections and vitamin malabsorption, which impedes proper growth and nourishment.

We don't have to look too far to help others and should never underestimate the positive force of one voice. In healthcare and medicine, one does not need to go to medical school to advance a cause and enact momentum that sparks progress (see [here](#) [12]). Small steps can become big ones. But, they are an essential component.

It just requires starting.

Do you know a celebrity doing good work that deserves recognition? If so, then please reach out to me by email or [Twitter](#) [13].

Happy to help any and all with ideas about how to give rare disorders or overwhelming, challenging diseases a megaphone. A short visit to a hospitalized patient breaks up the monotony more than you might imagine. So does a personal video or call from "their" star. Activities that are reminders of normalcy-- even if brief-- do wonders.

Between [Shannen Doherty's revelations on the meaning of remission](#) [14], Jimmy Kimmel's tale of [congenital heart disease](#) [15] and Ed Sheeran's consistent commitment to patient advocacy, the spotlight is only getting brighter. Looking forward to what next week brings from Hollywood in terms of meaningful health awareness.

Note(s):

(1) [Males with it often](#) [16] perish before birth or early infancy, but there are different variants. Over time, the child loses skills after an initial period of normal development. Coordination, communication and mobility are adversely influenced. Seizures and other health issues traditionally manifest. To learn more, see [here](#) [17] and [here](#) [18].

(2) It is progressive, robbing the individual of independence, sight, and intact cognition. To learn more about it and ways to help support efforts underway to develop therapies and a cure, go to this link at the [National Institute of Neurological Disorders and Stroke](#) [19].

(3) To understand further the importance of such an impetus to strive for cures of chronic disease, please review the following articles: [The Many Invisible Faces of Type 1 Diabetes](#) [20], [Men and Prostate Cancer: Fact Vs. Fiction](#) [21], [Did Gene Therapy Cure Sickle Cell Disease?](#) [22], [Dr. Jamie Wells on Al Jazeera TV Discussing Sickle Cell Anemia](#) [23], [Did Pompe Disease Get A New Champion In President Trump?](#) [24], [Pompe Disease, Newborn Screening And Inborn Errors Of Metabolism](#) [25].

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- [3] <http://www.acsh.org/news/2017/04/28/dear-hollywood-jack-black-shows-how-health-outreach-more-environmental-psas-11204>
- [4] <http://pagesix.com/video/ed-sheeran-gives-a-private-concert-for-a-sick-fan/>
- [5] <http://www.dailymail.co.uk/tvshowbiz/article-4471182/Ed-Sheeran-performs-concert-10-year-old-superfan.html#v-7208088419130690228>
- [6] <https://www.youtube.com/watch?v=psRo7IDCMp4>
- [7] [http://www.huffingtonpost.com/entry/ed-sheeran-melody-driscoll-hospital-visit\\_us\\_582c0ff1e4b0aa8910bdb6cf](http://www.huffingtonpost.com/entry/ed-sheeran-melody-driscoll-hospital-visit_us_582c0ff1e4b0aa8910bdb6cf)
- [8] <http://metro.co.uk/2017/04/25/ed-sheeran-grants-young-fan-suffering-from-batten-disease-his-number-one-wish-6597220/>
- [9] <http://mashable.com/2017/04/26/ed-sheeran-dying-fan-wish-come-true/#y3wk0IOSDgqf>
- [10] <http://people.com/celebrity/ed-sheeran-sings-to-dying-fan-triona-priestley/>
- [11] <http://www.nhlbi.nih.gov/health/health-topics/topics/cf>
- [12] <http://www.acsh.org/news/2017/04/19/5-fun-ways-impact-medicine-without-medical-school-11145>
- [13] <https://twitter.com/jamiewellsmd>
- [14] <http://www.acsh.org/news/2017/05/01/shannen-doherty-reveals-unspoken-truth-about-cancer-diagnosis-11210>
- [15] <http://www.acsh.org/news/2017/05/03/jimmy-kimmel-shares-newborn-sons-heartfelt-health-crisis-i-share-what-was-involved-11219>
- [16] <http://www.mayoclinic.org/diseases-conditions/rett-syndrome/basics/causes/com-20028086>
- [17] <http://rarediseases.org/rare-diseases/rett-syndrome/>
- [18] <http://ghr.nlm.nih.gov/condition/rett-syndrome>
- [19] <http://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Fact-Sheets/Batten-Disease-Fact-Sheet>
- [20] <http://www.acsh.org/news/2017/04/25/many-invisible-faces-type-1-diabetes-11182>
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[25] <http://acsh.org/news/2017/03/03/pompe-disease-newborn-screening-and-inborn-errors-metabolism-10947>