

FAPtalk SPRING ISSUE

March 29, 2017



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our transformation to rareLife solutions

By **Dan Donovan**



News Release: We've changed our name! We are now **rareLife solutions**.

On an everyday basis we engage with rare disease patients, advocates, foundations, pharmaceutical companies, physicians and agencies. Over time, we began to recognize that our name caused confusion and felt it should better reflect our mission to inspire collaboration, focus on our dedication to rare diseases and reflect our desire to support the rare disease community with insightful, innovative solutions. rareLife solutions was born! We look forward to sharing our successes with you going forward.

[Learn more about rareLife solutions](#)

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for the *medical* record

by Dakota Fisher-Vance



what I wished my doctors knew about Familial Adenomatous Polyposis

This intuitive article dedicated to the various healthcare professionals of the medical world, highlights key aspects about Familial Adenomatous Polyposis (FAP) that physicians need to be aware of in their practice, regardless of specialty. The most important, recurring theme is the fact that FAP is a multi-faceted disease not just limited to colon cancer. Written to directly address doctors, “For the *Medical Record*: What I wished my doctors knew about Familial Adenomatous polyposis” is a must read and a must share.

[read for the *medical* record](#)

recap: February 28, 2017 - Rare Disease Day

by **onevoice world**



about Rare Disease Day

Rare Disease Day takes place every year on the last day of February to raise awareness among the general public and decision-makers about rare diseases and their impact on patients' lives. Each year, organizations around the world hold a variety of activities that highlight rare and genetic diseases. This year, the theme was research and how research brings hope for the development of new, effective treatment options for rare diseases.

The rareLife team partook in awareness events up and down the east coast this year. In Washington D.C., our Community Engagement Team Leader joined over 350 rare disease advocates in learning about federal legislative issues affecting rare diseases, how to communicate with legislators, and strategies for effectively collaborating with each other.

Up at the Connecticut State Capitol, our co-founder and CEO and our Executive Vice President attended the Connecticut Rare Disease Day at the State House for the third year in a row. The day epitomized the collaborative effort that emanates throughout the rare space. The event was attended by about 200 patients, advocates, pharmaceutical company representatives, and CT state legislators, encapsulating rareLife solution's powerful vision of multi-stakeholder collaboration within the rare disease sector. For additional information on Rare Disease Day in the United States, please visit: www.rarediseaseday.us. For global activities, please visit: www.rarediseaseday.org.

spring into action

by **Dakota Fisher-Vance**



how to talk about colorectal cancer

We all know our poop says important things about us so why can't we say important things about poop to others? In honor of Colon Cancer Awareness Month, here's a guide on communicating about stool and two of the organs it travels through with everyone who poops (a.k.a., everyone).

[Learn How to Talk About Colorectal Cancer with Doctors, Friends, Family, Dates, and Strangers](#)

amplifying the patient voice

by **onevoice world**



rareLife at the World Orphan Drug Congress (WODC)

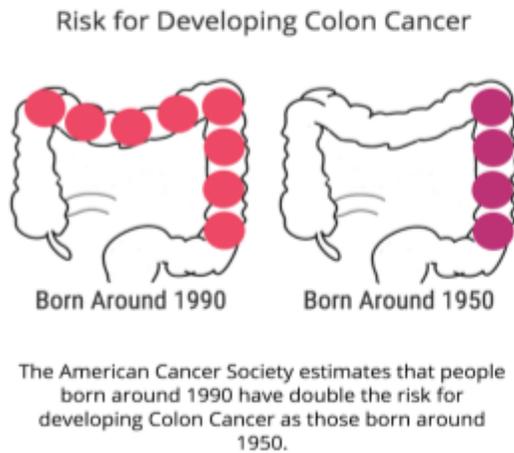
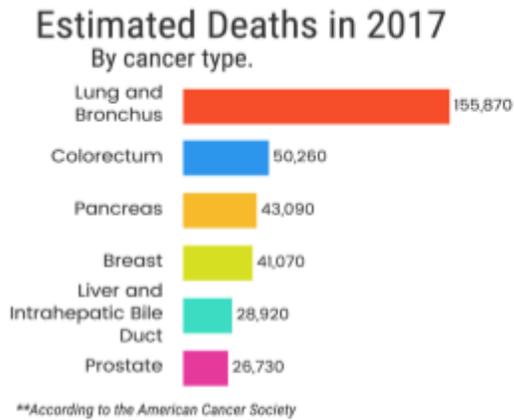
From a spark to a blaze: the rareLife team will be firing up the community voice at a pre-conference workshop scheduled to take place at the World Orphan Drug Congress. At this workshop, attendees will have the exciting opportunity to learn about what industry and advocacy leaders are doing to build truly integrated rare disease communities and to identify the value drivers behind this new relationship paradigm.

There will be a Fireside Chat with Pfizer moderated by Tony Howell, co-founder and COO of rareLife solutions. Additionally, Dan Donovan, co-founder and CEO of rareLife solutions, will be moderating a Beachside Bonfire with Advocates. This will be a must attend event for anyone interested in amplifying the voice of the rare disease community.

[Learn more about the rareLife workshop at the WODC](#)

colon cancer stats

by Dakota Fisher-Vance



1 in 7 Colon Cancer diagnoses are in people **under 50**

There will be roughly

95,000
New Cases

of Colon Cancer diagnosed in 2017 according to the American Cancer Society

celebrate colon cancer awareness month by staying in the loop

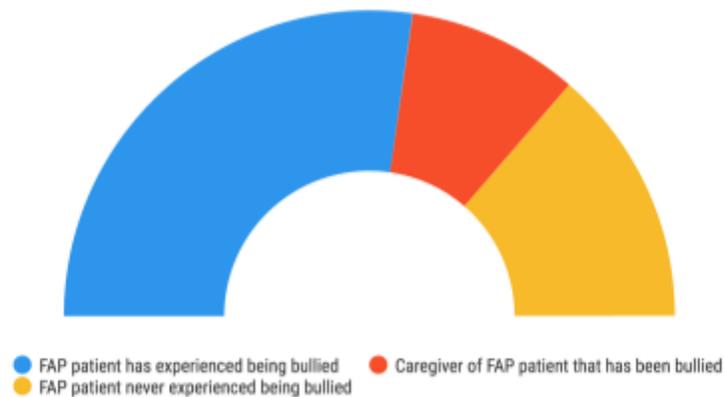
the FAP community experience with Bullying

Powered by FAPvoice rarePoll Distilled by Nadia Bodkin Pharm.D., M.S.



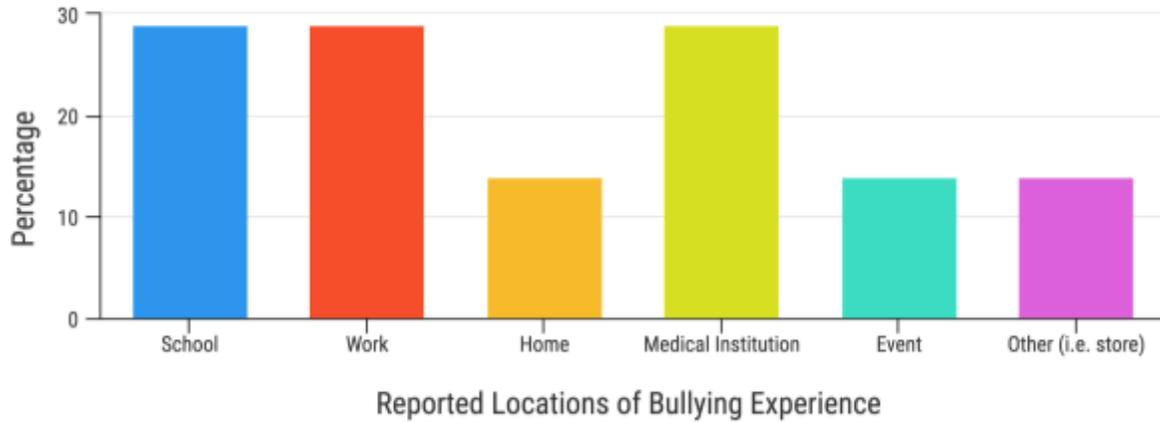
a snapshot of the FAP community's experience with bullying

More than 50% of FAPvoice respondents report the experience of being bullied



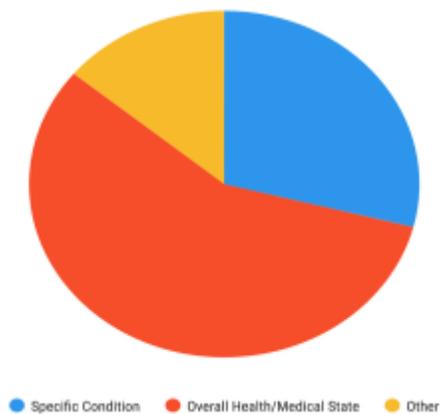
While Familial Adenomatous Polyposis (FAP) may be considered an “invisible” condition since upon first glance, you wouldn’t know if a person has FAP or not, the truth of the matter is that FAP is a “hidden” condition. Hidden conditions become exposed over time and through observation which leaves those living with not-so-visible chronic conditions, like FAP, susceptible to being bullied by others who learn about their health condition. When asked how many FAP people experienced being bullied, over 50% reported experiencing some form of bullying behavior as a direct result of having FAP.

Reported locations where bullying has taken place for FAP patients



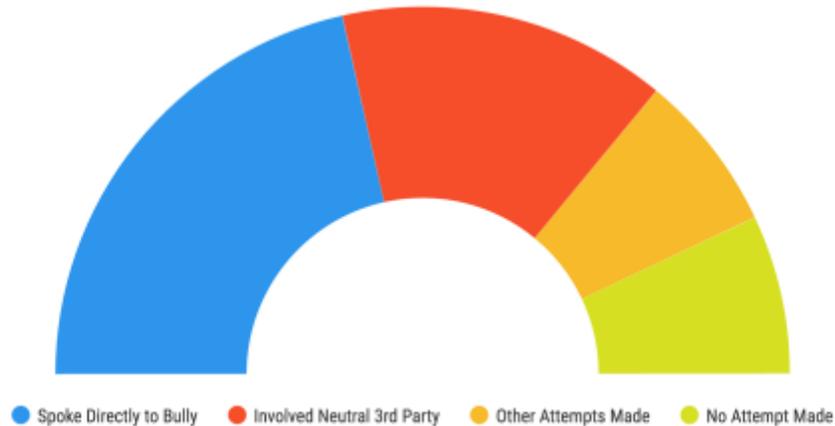
The three top locations that FAPvoice members report experiencing being bullied at are at school, at work and at a medical institution. When asked about the type of bullying that took place, approximately 71% of respondents reported experiencing the verbal type, which involves hurtful comments, name calling and teasing; while 28% of respondents reported experiencing the relational type, which involves using relationships to hurt the victim being bullied. It is important to note that one respondent reported experiencing the physical type, which involves shoving, pushing, tripping and other kinds of force. Zero respondents reported experiencing cyber bullying, which involves bullying attempts over cellphones, the internet, and social media.

Target of Bullying reported by FAPvoice members



57% of respondents reported that the specific target of the bully was their overall health and/or medical state. 29% reported that a specific condition (e.g. wearing an ostomy bag) was the target of the bullying experience and 14% reported another reason (one of which being “pain med use”).

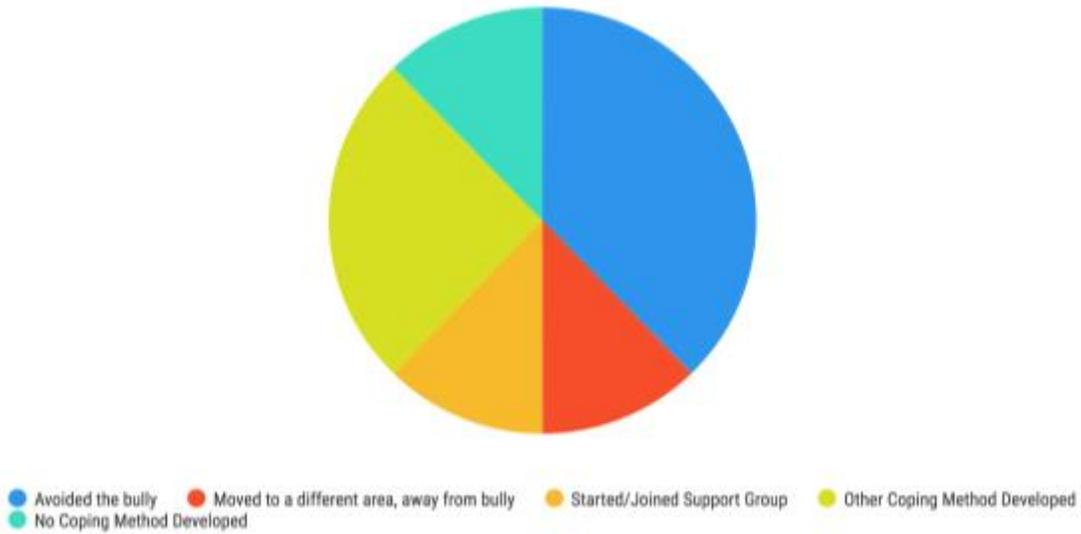
Attempts to resolve and/or address the bullying were made by 86% of respondents.



The majority of the members within the FAPvoice community who reported experiencing being bullied attempted to resolve their bullying issue. 43% reported speaking directly to or meeting with the bully(ies). 29% reported involving a neutral third party (e.g. school official, law enforcement, etc.). While 14% report not making any attempts to directly address and/or resolve the bullying, another 14% reported making other attempts to resolve the bullying matters (i.e. speaking to doctor in charge of staff).

The experience of being bullied for any reason is difficult for the victim and can have a lasting and permanent impact. As a direct result, individuals being bullied tend to develop coping mechanisms.

86% of FAPvoice respondents report developing coping methods.



43% of FAPvoice respondents report completely avoiding the bully(ies) as a coping mechanism. 14% reported moving to a different school, area, or workplace in order to escape their bully(ies). Another 14% reported joining or starting a support group meeting in order to cope with the effects of being bullied. Other coping methods were reported by 29% of respondents which included seeing a therapist and changing providers. Lastly 14% of respondents reported not developing any coping methods.

One way to help stop bullying within the FAP community is by speaking up. If you didn't have a chance to anonymously share you or your loved one's experience with bullying as a result of having FAP, there's still time to [take the survey on bullying](#).

Find these bullying survey results interesting? You're in luck! We distilled all of the results into the following [infographic](#). Feel free to share it and help raise awareness about this issue in the community!

A SNAPSHOT OF



the FAP Community's Experience with Bullying

powered by  members

More than 50% of FAPvoice respondents report the experience of being bullied



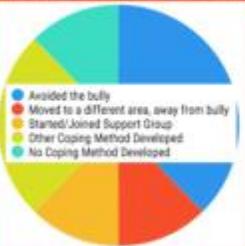
● FAP patient has experienced being bullied ● FAP patient that has been bullied, observed by Caregiver
● FAP patient never experienced being bullied



Top 3 Bullying Locations
Work
Medical Institution
School



More respondents felt their overall health was the target of bullying as opposed to a specific condition



F.A.P.ers are resilient
86% of respondents report developing a coping method

Attempts to address the bullying were made by 86% of respondents



● Spoke Directly to Bully ● Involved Neutral 3rd Party ● Other Attempts Made ● No Attempt Made



onevoice rare disease-specific “guided communities” provide sophisticated next generation software and professional management services for advocacy organizations and their constituents.

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