Long before Alyssa was ever tested for F.A.P., she witnessed the effects it can have on a person. Her father is a 3rd generation survivor; she has grown up watching her father going in and out of the hospital, knowing that the same fate could await her. At the age of 14, her and her brother were both tested. Both were diagnosed with Gardner’s Syndrome.

Her doctors immediately put her on anti-inflammatory medicine and she changed her diet to include anti-inflammatory foods. The results are staggering. Almost a decade later, her disease has remained ‘in remission’, which is to say that the polyps that had originally grown have since disappeared and no new polyps have taken their place. In fact, she just graduated college and is still ‘intestinally intact’ Anybody familiar with hereditary polyposis conditions knows what a feat that is.

Alyssa certainly knows how fortunate she is and takes nothing for granted. Last May, towards the end of her junior year of college, she started a blog about her personal journey with Gardner's Syndrome (GS). She focuses on the positive ways having GS has affected her life. (You'll have have to read her blog to find out more! The URL is below) She has enjoyed sharing her story so much that she recently turned her blog into an ebook entitled “The Waves of Life: Going Against the Tide”.

You can find it on Smashwords for purchase and download.

In addition to working through her senior year of college, and writing a book, she has managed to find the time to volunteer with the Familial Adenomatous Polyposis. She is currently helping us develop a questionnaire which will be used to develop a text- and audio-based list of FAQs designed to assist newly diagnosed HCC patients more easily navigate through the patient experience. And if that's not enough, she has her sights on a second book.


January 31st marked the end of our StartSomeGood fundraising campaign. We used SSG, an online fundraising platform, to raise the funds to develop our Patient Portal. In total, 35 people donated on the site raising over $3300! We received an additional $2000 contribution from an anonymous donor who also matched $3000 of the funds raised on SSG. The $8390 raised was very close to our desired goal of $10K, making this an amazing success!

We have since developed and brought online Phase I of our Patient Portal. Check out what many of you helped us to build by visiting www.HCCTakesGuts.org. Phase II of the Patient Portal will include educational resources, like webinars featuring medical professionals, and peer support opportunities, such as video-based online meetups.

(c) 2013 Familial Adenomatous Polyposis Foundation. Familial Adenomatous Polyposis Foundation is a registered charitable organization in the State of Illinois. Tax-exempt status under Internal Revenue Code Section 501(c)(3) applied for and pending.
Fact: Every business needs a cool logo. Ours is called the 'DNA-Dude'. Drawing upon his background in science, Travis Bray conceptualized incorporating two key aspects of hereditary colon cancer: the genetic-dependence and the primary form of treatment, colectomy. Shawnie Bray took his idea, and horrible sketch drawing, and produced the sketch you see to the right, while sitting in a café. The logo has been through several iterations before arriving at its present design.

Incorporating the double helix into the design, along with 'It Takes Guts' written across, and blocking out, the midsection, fulfilled Travis' vision for the logo. The final version is colored blue, matching that of the blue colon cancer ribbons, to give homage to the third element of HCCs: the unfortunate tendency to develop colon cancer. We salute all of those who were not only born with a HCC, but also fought the good fight against cancer!

Our growth and development would not have been possible without support from the many people who have donated their time and skills to help us out. Brad Podowski (BP+ Video+) and Mark Westman were both instrumental in the birth and evolution of our logo. Michelle Beem (Board Member and Secretary) was amazing during the lead up to our August Fundraiser and Launch event. She has also contributed to the development of the Patient Portal. Presently, Alyssa Ziegler, Lauren Pourian, and the (anonymous) creator of FAPulousTV on YouTube and Facebook, all three F.A.P. warriors extraordinaire, are working on content for the Patient Portal. All of their efforts have been invaluable. Volunteer opportunities abound right now at the Familial Adenomatous Polyposis Foundation. Projects range from a single four hour stint to 10 hours per month. If you have time to spare, please contact us at volunteer@fapfoundation.org or visit our website (www.HCCTakesGuts.org) for more information.

In January, a family that has been touched by F.A.P. reached out to us during a very difficult time. The person that reached out to us, who we will anonymously refer to as Chris, has three children, one of which was born with F.A.P. and has already undergone a total colectomy. Chris' father recently passed and was very devoted to his grandchildren. Chris requested donations be sent on behalf of her father in lieu of flowers for the funeral. We are deeply humbled to receive such consideration and wish to honor his memory. We continue to keep Chris in our thoughts and wish her family well.

We are excited to announce receipt of our Letter of Good Standing by the IL Attorney General on January 22nd. This was promptly followed by approval for pro bono legal assistance via The Law Project. Since March 3rd, the Familial Adenomatous Polyposis Foundation has been working under the IRS 501(c)3 tax-exempt shelter. These legal filings were a massive hurdle for us and mean that all donation are tax exempt! Contributions from friends and family (like you!) raised at our August Fundraiser and through the latter part of 2012 were integral for this to be possible!

We are in the early stages of developing our webinar series. Webinar topics will cover the gamut of issues faced by people living with or affected by hereditary colon cancer such as genetic testing, nutrition, screening and treatments, etc. Our first webinar will be sponsored by Myriad Genetics and will provide information about role, importance, and methods of genetic testing in our community. The date and title are yet to be determined so check the website for more information: www.HCCTakesGuts.org. If you have an idea for something you’d like to learn about, contact us at info@fapfoundation.org.