

ELIZABETH PULSIFER-ANDERSON

SUMMARY OF QUALIFICATIONS

- Created a support group that grew to include chapters, highly trained parent volunteers, members all over the world, two offices, a small staff, a #1 ranked web site with 300 information pages and 110,000 searchable postings taking over 1 million hits per month.
- Initiated collaborations with pharmaceutical companies on a Quality-of-Life study and a national public outreach campaign.
- Took sick children to Capitol Hill as a living science display. The kids were so memorable and enthusiastic that we were invited to testify.
- Initiated the controversial theory that GERD can be genetic and identified a research team that received NIH funding, mapped a gene and published in JAMA.
- Published the first consumer medical book on pediatric GERD.
- Wrote a plain language article on a baffling medical topic that was published in a peer-reviewed journal and re-posted on over a dozen large medical web sites.

RELEVANT EXPERIENCE

HEMECARE CONSULTANT / SALES

Visiting Angels

Visited dozens of referral partners and potential referral partners every week.

- Developed relationships with skilled nursing facilities, hospitals, assisted living, independent living, community centers and physicians' offices to ensure a continuous flow of client referrals.
- Made formal and informal presentations to decision-makers at every referral source. Identified strategic networking and community exposure opportunities.
- Researched additional types of referral sources and gathered data on them.
- Sponsored in-service trainings and hired speakers.
- Attended health fairs and community events including strategizing appropriate booth décor, collaterals and give-aways.
- Conducted home-care assessments with clients and families and signed service contracts.
- Conducted analyses of competitors regarding services provided, costs and relevant details.
- Provided a continuous stream of ideas for social networking and wrote stories about clients and referral sources.

BOARD MEMBER, EXECUTIVE DIRECTOR

The Conte Foundation

- Resurrected a dormant nonprofit dedicated to preventing harm from Reglan and other dangerous products.
- Worked with a scientific board, lawyers.

ADVOCACY MANAGER

Alpha 1 Foundation

- Brought over 50 families and critically ill individuals who don't travel well to Washington DC to testify before the FDA.
- Tripled the number of members interested in advocacy.

EXECUTIVE DIRECTOR/FOUNDER

Pediatric Adolescent Gastroesophageal Reflux Association

- Founded a patient support group that expanded to become an international advocacy organization. At the time, few doctors were aware of this condition and it was considered very rare.
- Fast and prolific writer of web content, quarterly newsletters, peer-reviewed medical journal articles, press releases, feature stories and a book. One article was heavily plagiarized and reposted on a dozen reputable sites such as WebMd.
- Translated very complex medical information into plain language for patients with reading levels from 10th grade and comic book style requiring no true reading ability.
- Editor and primary author for Reflux Digest, a newsletter consisting of ≤100 pages annually with summarized medical journal articles, meeting abstracts, media coverage, original content from physicians and patient stories.
- Initiated a study of inherited GERD and started a gene mapping study that was published in JAMA and changed the way that medical researchers collaborate with patient organizations. Became the human subjects recruiter when the study received NIH grant funding and wrote invitations that received 80% positive responses. (A 10% response is excellent.)
- Recruited one of the earliest groups of child lobbyists and helped them learn to tell their medical stories in Washington DC. We testified before a US Congressional committee.

AUTHOR

The Reflux Book, A Parent's Guide to Pediatric Gastroesophageal Reflux

- Wrote a 288 page book on acid reflux in children with foreword written by Dr. Bill Sears.
- The book addresses both the basic reflux concepts and many complex topics.
- The writing style of the book is reader-friendly and incorporates 100+ stories from real parents. The 10th grade reading level does not feel dumbed down even to medical professionals.

PUBLISHED 2007

CERTIFIED NURSE'S AIDE

Ames Visiting Nurse Service

- Specializing in depressed, elderly and clients with dementia.
- Included some clients with major disabilities, cancer patient, hospice clients and even occasional infants.

PARAPROFESSIONAL LISTENER – VOLUNTEER

Open Line

- Answered crisis calls ranging from suicide to rape crisis and substance abuse at community hotline for a college and surrounding towns. Information and referral calls ranging from homework help, to community resources to television programming.

PUBLICATIONS - HIGHLIGHTS

- “The Reflux Book, A Parent's Guide to Gastroesophageal Reflux,” 2007.
- “Recognition of movement disorders: extrapyramidal side effects and tardive dyskinesia - Would you recognize them if you see them?” Primary author. Peer reviewed. *Practical Gastroenterology*, May 2003.
- “Reflux Digest.” Newsletter. Editor and primary writer 1994-2014, 10-100 pages/year.
- Editor and primary content writer for www.reflux.org 1994-2014.
- “Mapping of a Gene for Severe Pediatric Gastroesophageal Reflux to Chromosome 13q14.” Contributing author. *Journal of the American Medical Association*, July 19, 2000.
- “National Institutes of Health Recommends the Routine Use of H2Blockers in Preterm Infants be Carefully Evaluated.” *Neonatal Network*. Simplification of a complex article by Ronnie Guillet. May/June 2006.
- “Helping Families Understand and Manage Pediatric Gastroesophageal Reflux.” *Zero To Three Journal*, January 2009.
- “Katie's Blood Clot Survival Story- Age 16. Slender. Non-smoker. At risk for a blood clot from birth control? Yes!” Written for www.stoptheclot.org.
- Several local magazine articles, numerous letters to the editor in local newspapers and the Washington Post.
- USA Today pull-out section on “Digestive Wellness.” Lead article.
- Consulted for Astra Zeneca on this study: Simultaneous development of the Pediatric GERD Caregiver Impact Questionnaire (PGCIQ) in American English and American Spanish.
- “Got Heartburn? Understanding the molecular culprits behind a common ailment.” *Gene Letter*, May 2001.

Writing samples available at www.ClarityWritingAndEditing.com/portfolio. Includes “before and after” examples.

MEDIA COVERAGE - HIGHLIGHTS

- “The DNA Age: Insurance Fears Lead Many to Shun DNA Tests,” *New York Times*, 2/24/08.
- “With Birth Control Pills, New Isn't Always Better,” National Public Radio, *Morning Edition*, 8/23/10.
- “Baby Crying? Doctors Say It May Be Acid-Reflux Disease,” *Wall Street Journal*, syndicated, 7/22/08
- “Clear Concerns amid Murky Debate: Patient Documents Raise Questions in Dispute on Endoscope Infection Risk,” *Boston Globe*, 3/27/02.
- “Bundle of Misery; The Diagnosis for an Inconsolable Infant Might Be Reflux, Not Colic. For Parents: How to Recognize the Problem . . . and Help Treat It,” *Washington Post* 8/27/02
- “What's Wrong with Katie,” *Nursing Spectrum*, November 1999 (Ghost writer)
- “A Baby with Reflux, a Family in Tumult,” *Washington Post*, 3/12/96
- NIH, NIDDK newsletter, feature article.
- “Possible Genetic Cause for a Childhood Ailment,” **Washington Post**, 7/19/00
- “The Role of Patient Associations in Research: Collaboration in the Search for a Genetic Marker for Reflux,” *V-Gastroenterology*, July 2000
- “Some Acid Reflux may be Partly Genetic,” *Reuters Health Wire*, 7/18/00
- After my daughter's friend was sexually assaulted at Tuscarora High School during school hours, she and her family asked me to take their story to the media to encourage other victims to come forward. There is a series of articles starting in November 2006 including local Frederick newspapers, DC television channels, *WTOP* and an *AP* wire story
- “Key Concepts in Online Health: e-Patients as Medical Researchers.” Profiled in the original “Ferguson Report” (now *Journal of Participatory Medicine*)
- “7 Million Babies and Children and 6 Million Hispanics In The U.S. Have Acid Reflux”, (Short title = “Babies get GERD too”), *Business Wire* and *NAPS* 9/15/09 Picked up by 352 English media outlets and 24 Spanish language outlets
- Television and radio interviews, including audience call-in formats.

EDUCATION

- Iowa State University, Ames IA. Double major sociology and psychology.
- Georgetown University, Washington DC. Paralegal classes at request of employer.
- Montgomery College, Germantown, M.D. Biology.
- Community College Baltimore County, Catonsville, MD. Anatomy, Physiology, Medical Terminology, Occupational Therapy Asst.
- NIH Plain Language Certificate.
- NIH, Office of Human Subjects Research, training on recruitment, ethics and confidentiality required by all NIH contractors and sub-contractors.
- CDC Health Literacy training.
- Grant writing workshops from The Foundation Center.
- Nonprofit management workshops on marketing, public relations, events, etc.
- AmeriCorps Host Agency training and Volunteer Coordinator workshops.
- Media and message training through Ogilvy PR Worldwide.

RELEVANT SKILLS

- Ability to understand complex scientific information, medical terminology.
- Experience with medical literature searching.
- Interest in social marketing, low literacy materials, plain language, participatory medicine.
- Superb in a crisis and think fast on my feet, even in a Medevac.
- Formerly Fluent in Spanish and German, minimal French.
- Sensitive to cultural and race issues.
- Can converse with both the uneducated and high-level professionals, individually or simultaneously.
- Extensive experience attending medical lectures and summarizing meetings.

AWARDS

- Nancy Dworkin Award for Outstanding Service to Youth, sponsored by the Montgomery County Commission on Children and Youth.
- Health On The Net awarded a symbol of excellence to www.reflux.org in 1998.

MEMBERSHIPS AND BOARD POSITIONS

- Frederick County Public Schools Rape Prevention Task Force.
- Washington Council of Governments Shaken Baby Syndrome Prevention Coalition.
- Genetic Alliance.
- Digestive Diseases National Coalition – board.
- Mom’s Clubs, first chapter in Washington DC – board.
- Stop the Clot and National Blood Clot Alliance – board.
- The Conte Foundation – board.

VOLUNTEERING

- Hospice – in high school and college.
- Community Hotline – high school and college.
- Classroom and ADD groups when my kids were little.
- Girl Scout Leader, Boy Scout assistant working with the kids who had learning issues.
- Disabilities dance class using ceiling track harnesses for non-ambulatory children.
- Home visits with kids on the autism spectrum – they trust me and I understand them.

RELEVANT PERSONAL EXPERIENCES

Caring for family members learning disabilities, failure to thrive and feeding disorder. Experience dealing with family dynamics that are affected by changes in health status, babysat for several children on the autism spectrum and with ADHD. We played at the park with a neighbor who worked for Infants and Toddlers.

My daughter was screened, tested and followed by Infants and Toddlers. My son was screened and tested by Child Find. Volunteered at my child's school to work individually with children who needed extra care. I helped one girl who "hated" math by creating silly problems with 100 digits and teaching her tricks. She later took calculus in middle school.

As a reflux expert, I am a frequent speaker for the Infants and Toddlers programs in Montgomery County.

As a prospective OTA student, I arranged to shadow several OTs who work in the intensive program and visit children in their homes. I particularly enjoyed working with kids on the spectrum. I find it easy to understand their behavior. One mom was trying to extinguish her son's attempts to disassemble her stereo speakers until I asked him if he was trying to get the music out. We taught him to turn on the stereo across the room and this solved the problem.

As an OTA student, I volunteered with a dance class for children with disabilities. I was assigned to a child who had been dropped and had trust issues. By the end of the hour, she jumped into my arms and her mother nearly cried. I also volunteered with another young girl who doesn't trust anybody but her mom. Within a few sessions, she was actively cuddling me.