

Sarah Ziegler
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QUALIFICATIONS:

- Course/Conference organizer national and international, formatting of all printed materials.
- Fundraising, marketing, media public relations, formatting of all printed materials.
- Event planner: for fundraising and other educational functions.
- Grant Writing: locates and prepares grants for research projects; prepare grants for educational programs, conferences for principle and co-investigators.
- Institutional review board (IRB) preparation: prepares submissions for principle and co-investigator for retrospective, prospective and other evidence based medicine clinical studies.
- Webmaster: design/format website templates, format & edit including upload web videos into custom video player & format/upload PDF's, graphic design including logo's, format pictures up load into custom album, site map & search engine, format all text, maintain site statistics, linking to other websites, issue/maintain email addresses, user submit forms & encryption protocol SSL 3.0, RC4 with 128 bit (High) RSA with 1024 bit exchange, credit card donation, submit/maintain Google status including XML, ROR, HTML, Google add words including search terms and creating adds. FTP website upload.
- Other computer office skills include complete use of Microsoft office professional 2003&2007, Adobe Creative Suit 3 Design Premium.

EXPERIENCE:

Organizations Established (Two)

2000–2005

- **Co-Founder, The MHE Coalition**, National Director & Coordinator of Research, Executive Director MHE Patient Registry, responsibilities & accomplishments included of the following:
 - **Working jointly** to officers to obtain 501c3
 - **Establishment** of Medical & Scientific Advisory Board.
 - **Establishing** a network of new researchers, orthopaedic physicians, and patients.
 - **Studies published** results of new research established and or use of patient registry.
 - Hereditary multiple exostoses and heparan sulfate polymerization: Zak BM, Crawford BE, Esko JD. *Biochim Biophys Acta*. 2002 Dec 19;1573(3):346-55
 - Mice deficient in Ext2 lack heparan sulfate and develop exostoses: Stickens D, Zak BM, Rougier N, Esko JD, Werb Z. *Development*. 2005 Nov;132(22):5055-68. Epub 2005 Oct 19.
 - Hereditary multiple exostosis and pain: Darilek S, Wicklund C, Novy D, Scott A, Gambello M, Johnston D, Hecht J. *J Pediatr Orthop*. 2005 May-Jun;25(3):369-76.
 - **Initiate The First MHE Research Conference**, (multi disciplinary all fields relating to MHE 19 speakers) held Oct 2002 Arizona Cancer Center locating a PI's (Jeffrey Esko, PhD. & Scott Selleck, MD, PhD) to co-organize conference along with myself, grants, conference budget, speakers list, hotel, welcome reception, dinner banquet, format abstract book.
 - **2003 Administrative** and funding support for the Society for Glycobiology conference satellite meeting, Human Glycosylation Disorders, Hudson Freeze, PhD. and presentation during advocacy organizations how they relate to research.
 - **2005 Initiate Second International MHE Research Conference**, (multi disciplinary all fields relating to MHE 30 speakers) held at the Shriners Hospital Houston locating a PI's (Dan Wells, PhD & Jacqueline Hecht, PhD) to co-organize conference along with myself, locate conference date, chair breakout patient session 5 hours, grants & 90 day follow up grant reports, conference budget, speakers list, hotel, welcome reception, dinner banquet, format abstract book and clinical information for breakout session.
 - **2002 Initiating the setup of CLIA Certified PCR Genetic Testing** of the EXT1 & EXT 2 gene, locating laboratory & funding, testing review. [Gene Dx](#)

○**Fundraising:**

- **2002-2005 Co-Chair** of all event planning for MHE Golf Outings, silent auctions & formatting of all event materials. Held in New Jersey.
- **2005 Co-Chair** of all event planning for the FUNTASIA 2005 Research Banquet, formatting of all event materials and press releases, obtaining of Citations, Proclamations and Certificates of Recognition from the U.S. Congress, N.Y. State Senate, N.Y.C Council, presented to Dan Wells, Ph.D. Professor of Biology and Biochemistry, University of Houston, Houston, Texas. Held in New York City.
- **2000-2005 Authoring news letter articles** & obtaining professionals to author articles (eighteen news letters published averaging 18-20 pages)

2006–Present

- **Co-Founder, The MHE Research Foundation**, Vice President & National Director of Research.
- **Executive Director, The MHE National Research Registry.**
- **Coordinator of Clinical Information.**

Responsibilities and accomplishments the following:

- **Working jointly** with the Foundation President Craig A Eaton, Esq. to obtain 501c3
- **Establishment** of both a [National & International Scientific & Medical Advisory Board](#), including board responsibilities.
- **Continue growth** of network of new researchers, orthopaedic physicians, and patients.

Studies published results of new research established and or use of patient registry.

- **Henry H. Rohel, Ph.D.**, Dept of Biomedical Science, The University of Sheffield, UK.
 - Regulation of Zebrafish Skeletogenesis by ext2/dackel and papst1/pinscher: Aurélie Clément, Malgorzata Wiweger, Sophia von der Hardt, Melissa A. Rusch, Scott B. Selleck, Chi-Bin Chien, Henry H. Roehl. 2008 PLoS Genet 4(7): e1000136. doi:10.1371/journal.pgen.1000136
- **Maurizio Pacifici, Ph.D.**, Director of Orthopaedic Research, Professor in the Department of Orthopaedic Surgery Thomas Jefferson University College of Medicine, Philadelphia, PA.
 - Conditional Kif3a ablation causes abnormal hedgehog signaling topography, growth plate dysfunction, and excessive bone and cartilage formation during mouse skeletogenesis: Koyama E, Young B, Nagayama M, Shibukawa Y, Enomoto-Iwamoto M, Iwamoto M, Maeda Y, Lanske B, Song B, Serra R, Pacifici M. Development. 2007 Jun;134(11):2159-69.
 - Development of new EXT mice model to be presented during 2009 MHE conference.
- **Yu Yamagichi, MD, PhD**, Professor, Sanford Children's Health Research Center, The Burnham Institute, La Jolla, CA. (seed funding provided)
 - Development of new EXT1 mice model to be presented during 2009 MHE conference.
- **John P. Dormans, M.D.**, Chief of Orthopaedic Surgery, The Children's Hospital of Philadelphia; Professor of Orthopaedic Surgery, University of Pennsylvania School of Medicine, PA
 - Abnormal scarring with keloid formation after osteochondroma excision in children with multiple hereditary exostoses: Hosalkar H, Greenberg J, Gaugler RL, Garg S, Dormans JP.: J Pediatr Orthop. 2007 Apr-May;27(3):333-7.
- **Judith V.M.G. Bovée, MD, PhD**, Department of Pathology, Leiden University Medical Centre, Leiden, The Netherlands.
 - Multiple osteochondromas: Judith V.M.G. Bovée, Orphanet J Rare Dis. 2008; 3: 3. Published online 2008 February 13. doi: 10.1186/1750-1172-3-3.
- **Facilitate** the transfer of mice models and other reagents.
- **Establishment** of strong relationships with scientific and orthopaedic societies.
 - MHE Research Foundation is an [affiliate of the Society for Glycobiology](#)
 - Participating member of the United State Bone Joint Decade (USBJD)
 - Under the auspices of [USBJD leadership role within the Rare Bone Disease Patient Network](#).
 - Active member of the Genetic Alliance & NORD
 - Strong working relationships with the following

- [Pediatric Orthopaedic Society of North America](#)
 - Initiate the first breakout session at the 5th International Pediatric Orthopaedic Symposium. Advisor to Charles T Price, MD and John P. Dormans, MD
- American Academy of Orthopaedic Surgeons
 - Approved to exhibit at AAOS CME courses ID number: 0027047
- The Connective Tissue Oncology Society
 - **2007** Presentation at CTOS conference held in Venice Italy. How advocacy relates to research and the improvement of clinical care. Establishment of [Patient advocacy group section on the CTOS website](#).
 - American Society for Matrix Biology 2008, [Partnering Society 2009](#)
 - **2009** [Gordon Glycobiology Conference](#) administrative support Hudson Freeze, PhD and funding.
 - **2010** USBJD for Rare Bone Disease Patient Network application granting of educational booth display and poster during conference POSNA conference.
- Initiate the [Third International MHE Research Conference](#), (multi disciplinary all fields relating to MHE 33 speakers) Location of city to be held Boston, locating a PI's (Yu Yamaguchi, MD, PhD,) to co-organize conference along with myself, grants & 90 day follow up grant reports, conference budget, speakers list, hotel, conference room & auto/visual arrangements, welcome reception, dinner banquet, format abstract book, Ready Talk video conference, dimension of information (meeting reports for journal publication, posts of conference in major societies and other related venue)
- **Fundraising:**
 - **2007 Co-Chair** of all event planning for the FUNTASIA Research Banquet, formatting of all event materials and press releases, creation and presentation of "The Humanitarian Scientific Achievement Award", obtaining of Citations, Proclamations and Certificates of Recognition from the U.S. Congress, N.Y. State Senate, N.Y.C Council, presented to Yu Yamaguchi, MD, PhD Professor, Sanford Children's Health Research Center, The Burnham Institute, La Jolla, CA and Dominique Stickens, Ph.D., Senior Research Biologist, Merck Research Laboratories, NJ
 - **2009 Co-Chair** of all event planning for the [FUNTASIA Research Banquet](#), formatting of all event materials and press releases, presenting "The Humanitarian Scientific Achievement Award", obtaining Proclamation from entire N.Y.C Council, Citation office of the President Borough of Brooklyn State Senate, Legislative Resolution honoring John P. Dormans, M.D., Chief of Orthopaedic Surgery, The Children's Hospital of Philadelphia.
 - **2006-2009 Co-Chair** of all event planning for the [MHE Golf Classic](#), silent auctions & formatting of all event materials.
- **2006-2009 E-News Letter**
- **2006-2009 Establishment of patient** educational information guides and clinical forms.
- **2008 Initiator of the 145pg MHE guide book**, editor, authored chapter/supportive text within and obtained both professionally written chapters & reprint copyright for journal publications included at the end of the book.

"The Connections Corner Guide to MHE/MO/HME
 Multiple Hereditary Exostoses
 Multiple Osteochondroma
 Hereditary Multiple Extostoses"

Awards

- **2005 New York State Assembly: Certificate of Merit**, awarded for personal efforts on behalf of MHE
- **2005 U.S. House of Representatives: Certificate of Recognition**, awarded for personal efforts on behalf of MHE
- **2005 & 2007 New York City: Proclamation**, MHE Research Foundation
- **2009, New State Senate Legislative Resolution Honoring the MHE Research Foundation** and awarded for personal efforts on behalf of MHE

Webmaster

2006–2009

- **Website The MHE Research Foundation**, www.mheresearchfoundation.org all skills above used. Website reviews links granted societies/organizations to the following: NIH Genetics Home Reference, (HON) Health on the Net Foundation, accreditation granted 2006 #282463, The Disease Data Base a cross-referenced index of human disease granted 2006, Society for Glycobiology, EuroBoNet, POSNA, USBJD, ASMB, CTOS, text & links placed on Wikipedia, links placed on verity of academic institutional websites.

2009

- **Website Dror Paley, MD, FRCSC**, www.limblengtheningdoc.org all skills above used. Links placed on Ortho Fix, ISKD, Eight-Plate, Limb Lengthening and Reconstruction Society, text & links placed on Wikipedia & patient support organizations as well as parent blogs.

Institutional review board (IRB) preparation

2001

- **IRB #010396** for Tumor/blood sample collection for Jeffrey D Esko, Professor, Dept. of Cellular Molecular Medicine, Co-Director, Glycobiology Research & Training Center, UCSD, San Diego CA.

2006–present

- **IRB #UA-A04-64 Collaboration [EuroBoNet](#) & MHE Research Foundation** (US leg of project) tumor/blood/clinical information IRB submissions to the following under the auspices the MHE National Research Registry acting Liaison Officer, University of Antwerp, Department of Genetics, Belgium under the direction of [Wim Wuyts PhD](#) and the Rizzoli Orthopaedic Institute, Genetics Unit, Bologna Italy [Luca Sangiorgi, MD, PhD](#).
 - **John P. Dormans, M.D.**, Chief of Orthopaedic Surgery, The Children's Hospital of Philadelphia; Professor of Orthopaedic Surgery, University of Pennsylvania School of Medicine, PA
 - **Alexandre Arkader, M.D.**, Director Musculoskeletal Tumor Program, Children's Hospital Los Angeles CA
 - **Charles T. Price, M.D.**, Arnold Palmer Hospital for Children, Director of Pediatric Orthopaedic Education, Associate Director Orthopaedic Residency Program, Professor of Orthopaedic Surgery, University of Central Florida College of Medicine.
 - **Multiple Shriners Hospitals.**
 - **Preparation** of all tumor collections boxes and insuring all boxes get through customs.
 - **First project publication:** Mutation screening of EXT1 and EXT2 by denaturing high-performance liquid chromatography, direct sequencing analysis, fluorescence in situ hybridization, and a new multiplex ligation-dependent probe amplification probe set in patients with multiple osteochondromas: Jennes I, Entius MM, Van Hul E, Parra A, Sangiorgi L, Wuyts W.J Mol Diagn. 2008 Jan;10(1):85-92. Epub 2007 Dec 28.
 - **Second project publication:** Multiple osteochondromas: mutation update and description of the multiple osteochondromas mutation database (MODb). Jennes I, Pedrini E, Zuntini M, Mordenti M, Balkassmi S, Asteggiano CG, Casey B, Bakker B, Sangiorgi L, Wuyts W. [Hum Mutat. 2009 Oct 6](#)

Other advocacy and community activities

2000-2003

- **Learning leader** for NYC Public School PS79

2003

- **PTA President**, Chair of fundraising 2001-2003, served on numerous committees, editor & formatted hard cover color school yearbook 2003

2002-2009

- **Advocacy** for disabled children concerning NYC schools, Individualized Education Plan (IEP) & Section 504, when requested was parent reprehensive at face to face appeals. There is also an entire section on this located on the MHE Research Foundations website.