



SBA-Supported Research Studies and Requests in 2020

1. Benefit-Finding and Growth in Adolescents and Young Adults with Spina Bifida, Loyola University Chicago
 - Examine ways in which individuals with Spina Bifida may experience positive life changes and growth due to their Spina Bifida.
 - Contact: Tessa K. Kritikos, Ph.D., Post-doctoral Pediatric Psychology Fellow, tessakritikos@gmail.com, 610.764.0711
 - Status: Completed. Published, Journal of Health Psychology, 2021, "*Benefit-finding among young adults with spina bifida.*"

2. A Comparison of Caregivers' Experiences in Accessing Mental Health Treatment for their Children, Children's Friend, Inc., affiliate of Seven Hills Foundation
 - Study the experiences in and barriers to accessing mental health services for families. The study compares three groups – caregivers of children with one or more mental health conditions, caregivers of children with mental health conditions and common medical conditions, and caregivers of children with mental health conditions and rare disease.
 - Contact: Kim Hager, LICSW - khager@childrensfriend.org / Maria Martinez Calderon, LMHC - mmartinez@childrensfriend.org, 508-753-5425
 - Status: Pending review by SBA Medical Director.

3. In Utero Percutaneous Endoscopic Correction of Myelomeningocele: Laparotomy versus Percutaneous - Wellington Regional Medical Center, Wellington
 - Promote participation among Spina Bifida Patient Registry Clinics in a pilot study on human subjects. The study uses an FDA-approved fetoscopic myelomeningocele surgery.
 - Contact: Ruben Quintero, MD - q@the-fetal-institute.com / Eftichia Kontopoulos, M.D. - K@the-fetal-institute.com, 720-753-3825
 - Status: SBA included information about this study on spinabifidaassociation.org

4. The Genetic Investigation of Childhood Neurological Disorders, Gleeson Laboratory for Pediatric Brain Disease, Rady Children's Institute for Genomic Medicine, University of California, San Diego
 - Neurogenetic study to increase understanding of why some people are born with Spina Bifida
 - Contact: Joseph Gleeson, MD - contact@gleesonlab.org, (858) 246-0547
 - Status: Ongoing.

5. A Patient-Centered Approach to Urinary Incontinence and Quality of Life in Children and Adolescents with Spina Bifida (Goal-Setting Tool), Riley Hospital for Children
 - Study to better understand how incontinence affects people with Spina Bifida and what they want most from incontinence treatments.
 - Contact: Konrad Szymanski, MD - szymanski.konrad@gmail.com, 317-944- 7469
 - Status: Complete.

6. Incontinence and Daily Well-Being among Adults with Spina Bifida Study, Riley Hospital for Children
 - Study to help understand things about the sexuality of adults with Spina Bifida who have experienced incontinence.
 - Contact: Pat Brooks - pbrooks@iu.edu, (317) 274-9793
 - Study: Ongoing.

7. Sexuality in Adolescents with Spina Bifida, Riley Hospital for Children
 - Study to understanding things about the sexuality and sexual health of teenagers with Spina Bifida.
 - Contact: Devon J. Hensel, MS, PhD, FASHM - djhensel@iu.edu, (317) 274-8812
 - Status: Ongoing.

8. Impact of COVID-19 on Children, Adolescents, and Young Adults with Spina Bifida, Loyola University Chicago
 - Study to understand how the effects of the COVID-19 pandemic have impacted children, adolescents, and young adults with Spina Bifida and their parents.
 - Contact: Grayson Holmbeck, PhD - gholmbe@luc.edu, 773-508-2967
 - Status: Complete.

9. Research Project 1: Intravesical Probiotic for Urinary Symptoms (Indwelling) and Research Project 3: Connected Catheter Quality of Life Study, MedStar Bladder Rehabilitation Research Training Center (RRTC)
 - Project 1 will study healthy urine when not experiencing urinary symptoms, and estimate the effect of intravesical Lactobacillus GG dose on urinary symptoms
 - i. Contact: Margot Giannetti at Margot.Giannetti@medstar.net or 202-877-1071.
 - ii. Status: Ongoing
 - Project 3 will evaluate the burden on men with of Neurogenic Lower Urinary Tract Dysfunction (NLUTD) on Health-related Quality of Life (QOL), participation affected by type of bladder management, and determine what constitutes a clinically meaningful difference in Neurogenic Lower Urinary Tract Dysfunction

(NLUTD)-related QOL and participation and to identify NLUTD user-defined themes regarding bladder function and catheter-related barriers and the daily impacts on one's life.

- i. Contact: Mandy Rounds, PhD - Amanda.K.Rounds@medstar.net, 202-877-1591
- ii. Status: ongoing

10. Factors Influencing Patient Decision-Making when choosing Prenatal or Postnatal Myelomeningocele Surgical Repair, University of Cincinnati, Cincinnati Children's Hospital

- The study aims to identify the factors that influence patients to choose either prenatal or postnatal surgery to repair their child's Spina Bifida defect. A second aim is to identify what supports or resources patients need during this time.
- Contact: Corrie Fabelo - corrie.fabelo@cchmc.org
- Status: Complete and manuscript accepted by University of Cincinnati