Clinicians and psychologists at The Rothman Center for Pediatric Neuropsychiatry in St. Petersburg, Florida of the University of South Florida are looking for youth with Barth Syndrome, their sibling(s), as well as a parent/guardian to participate in a study investigating psychosocial functioning in youth with Barth Syndrome and their families. Youth with Barth Syndrome, potential siblings, and a parent/guardian will be asked to complete several paper/pen questionnaires about their functioning as well as how Barth Syndrome has impacted their life. Information gathered from this study will provide greater understanding of psychosocial effects of Barth Syndrome upon youth, siblings, and parents/caregivers, and may be helpful in determining whether any interventions may be helpful.

If you are interested, please call 727-767-8230 or e-mail Principal Investigator Dr. Marni Jacob at mjacob1@health.usf.edu and refer to the “Psychosocial Functioning in Barth Syndrome” study to determine if you qualify and to schedule an appointment, which will be held at the Rothman Center for Pediatric Neuropsychiatry in St. Petersburg, FL.

Study recruitment and participation will also take place at the Barth Syndrome Foundation Conference at the Hilton Clearwater Beach Hotel in Clearwater, Florida, held between June 23-28th, 2014.

(USF IRB # 16756, Principal Investigator, Marni L. Jacob, Ph. D.)