



LOYOLA UNIVERSITY MARYLAND

— 1852 —

Sociology

How do you cope with your craniofacial difference? Share your life experience living with craniofacial FD or cherubism in interviews with Dr. Amanda Konradi.



[Dr. Amanda Konradi](#), who served on the board of the Fibrous Dysplasia Foundation from 2004 to June 2016 as Secretary and Acting President, is a sociologist (and cherubism patient and parent to a child with cherubism). Her present project is to use her investigative skills to increase knowledge of the ways that patients understand their craniofacial conditions and make decisions about managing their facial differences. Dr. Konradi will be conducting guided open-ended interviews with adult women and men, ages 20 to 70, beginning with what their recollections of childhood and moving through adolescence into adulthood. Participants will also be asked to share 3-5 photos that capture their sense of self at a number of points in time. The end goal of this research is to produce better resources for patients and their parents as they confront diseases that are evolving and affect appearance, because surgery is not always a desirable or possible option.

Interviews will be conducted in person, if Dr. Konradi can drive to you, or conducted by video-conference software. Your first interview will take one-and-a-half to 2 hours and your second will be 30 to 60 minutes a week later, to allow you time to process and reflect.

The interviews will be audio recorded and then professionally transcribed. References to real names or other identifying information will be removed before data analysis begins. The de-identified data will be analyzed by Dr. Konradi, her collaborator [Dr. Robert Rubinstein](#), and selected student research assistants. Photographs will not be published.

Dr. Konradi has completed training in the proper treatment of human subjects through NIH and the Loyola University Maryland IRB has reviewed this project for compliance with ethical research practices. Your participation in this project will not affect your access to any treatment or the resources of the Fibrous Dysplasia Foundation. You also have the option to discontinue your participation at any time. You will receive an honorarium of \$50 after the second interview and a copy of your life story.

Please take this opportunity to build a research culture in the rare disease community. Your participation may help a younger person with craniofacial FD or cherubism or a parent with a newly diagnosed child.

Please contact Dr. Konradi if you are interested in learning more about participating and shaping the way craniofacial fibrous dysplasia is understood and treated: akonradi@loyola.edu or 410-617-5401 (messages).

To learn more about Dr. Amanda Konradi, please [visit her Loyola University Maryland bio-page](#). To learn about her previous work, inspect her [curriculum vita](#) or access her publications though [Academia.edu](#) or [Google Scholar](#).

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