



A Clarian Health Partner

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Section of Pediatric  
Cardiology  
Department of Pediatrics  
IU School of Medicine

Riley Research 127  
702 Barnhill Drive  
Indianapolis, IN 46202-5225

317-274-8906 office  
1-866-864-0855  
317-274-4022 fax  
800-622-4989 IMACS

[www.rileyhospital.org](http://www.rileyhospital.org)  
[www.clarian.org](http://www.clarian.org)

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Tiffanie Johnson, M.D.  
David K. Lawrence, M.D.  
Jacqueline A. Maiers, M.D.  
Julio Morera, M.D.  
Debbie Murphy, R.N.  
Transplant Coordinator  
R. Mark Payne, M.D.  
Michael Rubart, M.D.  
Marcus Schamberger, M.D.  
Weinian Shou, Ph.D.  
Lei Wei, Ph. D.  
Becky Will, R.N.

Dear Parent or Patient:

The purpose of this letter is to invite you to participate in a study of patients who have undergone spinal fusion surgery because of Friedreich's Ataxia (FA). As you know, patients with FA quite often require spinal fusion surgery to correct severe scoliosis (a bend in the spine). Sometimes these patients do not do well during spinal fusion surgery because their hearts are weak. We currently cannot predict who will have heart problems ahead of time but if we could, this would be of tremendous benefit to future patients. We are asking if you will help us figure this out.

We need to examine the medical records of patients undergoing spinal fusion surgery immediately before, during the surgery and hospital course, and after surgery. **This includes both those patients who have done well, and those who have not and may have died after surgery.** We are looking for clues that might help us learn to predict who will have problems with surgery. To do this, we need the following records:

1. Medical records from your **doctor's office** prior to and after surgery, **including cardiology workup reports (EKG and echocardiogram).**
2. Medical records from the **hospital** during surgery, including the intra-operative records, and post-operative records. **This includes records of cardiology workups (EKG and echocardiogram)** and anesthesia during surgery.

If you agree to participate in this study, you will need to sign an 'authorization to release medical records' for both your doctor(s) and the hospital. This has to be done by you and given to the doctor's office, or the hospital. After this, they will copy and ship the records to us at the address below. We also need you to sign and return the 'informed consent' to us. Any and all costs associated with these records should also be sent to us at the same address and we will pay for these (no cost to you).

Ship to: Dr. R. Mark Payne, MD  
c/o: Cari L. Petty  
1044 West Walnut, R4302B  
Department of Pediatrics (Cardiology)  
Indiana University School of Medicine  
Indianapolis, IN 46202 USA  
Phone: 317-278-6239  
e-mail: [clpetty@iupui.edu](mailto:clpetty@iupui.edu)

All personal identification in these records will remain confidential and will not be released in any fashion. The information within the records will be analyzed for clues about the health of the heart and the conclusions will be published. We cannot provide specific feedback or information to you about you or your child's surgery.

We hope you will agree to participate in this study. However, if you do not, we understand and this will not affect your access to medical care in any way. If you have questions about this study, please do not hesitate to contact us at the address or numbers above.

Sincerely,

R. Mark Payne, MD, FAAP, FACC  
Professor of Pediatrics (Cardiology)

