

**Thank you for your interest in our research study! Inside you will find the answers to many frequently asked questions about the study.**

**For more information, please contact our research group at**

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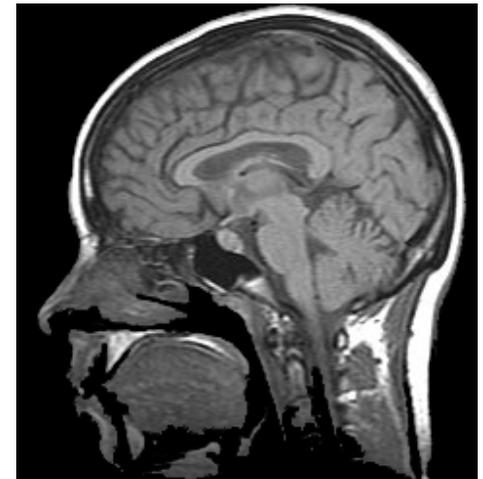
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# **Fibrous Dysplasia MRI & PET Research Study**



**Boston Children's Hospital**  
Until every child is well™



**P.A.I.N. Research Group**

A Leading Brain-Imaging Lab in Pain Research

**Q: Who is eligible?**

**A:** Patients diagnosed with Fibrous Dysplasia/McCune Albright Syndrome (FD/MAS) or healthy individuals.

**Q: What does this study involve?**

**A:** For FD patients, the study may consist of one or two visits. During the first visit, patients will be asked to complete a series of questionnaires, undergo pain sensitivity testing, lie in an MRI scanner while the study team measures your responses to pain and have their blood drawn. If eligible, patients may also be asked to come in for a second visit, where they will undergo a PET scan. The first study visit will last approximately 2-3 hours. The second study visit will last approximately 1-2 hours.

For healthy individuals, the study consists of one visit. Participants will be asked to complete a series of questionnaires, undergo pain sensitivity testing, lie in an MRI scanner while the study team measures responses to pain and have their blood drawn. The study visit will last approximately 2-3 hours.

Participation in this research will not alter or interfere with any of the standard clinical procedures or treatment that one would normally receive if not partaking in this research. All research studies will take place at Boston Children's Hospital.

**Q: What if I live out of town, can I still participate?**

**A:** Yes! If an FD/MAS patient lives outside of the Boston metropolitan area, our lab can book and pay for travel accommodations up to \$1000. If a FD/MAS patient or healthy subject lives within the Boston metropolitan area, we will reimburse individuals up to \$150 for travel related costs.



**Q: Will I get paid to be part of this study?**

**A:** A FD/MAS patient or healthy subject who participates in 1 study visit (MRI only) will be paid \$200. A FD/MAS patient who participates in 2 study visits (MRI + PET) will be paid a total of \$500.

**Q: What does the pain stimulation involve?**

**A:** Those who choose to participate in this study will experience pressure pain as well as thermal (cold and heat) pain. The pain stimuli will be applied to the base of the skull, back of the hand and leg. The pain stimuli will last 12 continuous seconds at most and will not cause any permanent injury, but it may cause temporary discomfort. If the pain becomes too uncomfortable, one can stop the stimulation at any time by telling a study staff member.

## Scan Information

**Q: What is an MRI scan?**

**A:** MRI (Magnetic Resonance Imaging) is a medical imaging technique that can take pictures of your body.

**Q: What are the risks associated with MRI?**

**A:** MRI does not involve any radiation and so there is no risk to most people. It does however involve a strong magnetic field, which although not harmful by itself, may cause implanted medical devices that contain metal to malfunction in patients who have them. Patients with any such devices are not eligible for the study.

**Q: What is a PET scan?**

**A:** PET (Positron Emission Tomography) is a medical imaging technique that measures body functions such as blood flow, oxygen use, and sugar metabolism to help doctors and scientist evaluate how well an individual's organs and tissues are behaving.

**Q: What are the risks associated with PET?**

**A:** PET is a highly sensitive technology that uses a radioactive substance to show the chemical and functional changes in the body. However, the exposure to radiation is minimal and substantially less than the average amount of background radiation a person would be exposed to over a 1 year period. Current BCH protocols are in place to keep radiation exposure as low as possible, while assuring high image quality.