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- Platinum membership - \$1000
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 Bronze membership - \$25
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My check for \$ _____ is enclosed.

Send to: Fibrous Dysplasia Foundation, Inc.
15 Browns Ct SE, Washington, DC 20003

- I will make my credit card donation to
order@fibrousdysplasia.org. through *www.Paypal.com*
 My employer has a matching gift program -
form enclosed
 Send me information about including the
FD Foundation in my will.

My gift is :

in memory of _____

in honor of _____

Please notify (name and address)

The Fibrous Dysplasia Foundation is a 501(c)(3) nonprofit organization. All contributions are deductible to the extent allowed by law. Tax ID# 02-0715210

How you can help

If you are a person with FD, MAS, or Cherubism or if you are a relative, friend or caregiver consider joining the foundation to help further our efforts. Visit our web site - www.fibrousdysplasia.org - to see our mission statement, plans and our accomplishments, as well as additional information.

We will periodically contact you with updates from the FD Foundation. Please consider sharing news of the website with your: health care providers, extended family members, friends, co-workers, clergy, teachers, and coaches. Your donation to the Fibrous Dysplasia Foundation will help expand our ability to help individuals, families, friends, and health care professionals learn more about Fibrous Dysplasia, McCune-Albright Syndrome and Cherubism. Make credit card donations through www.Paypal.com. Payment can be made to order@fibrousdysplasia.org.

The FD Foundation has been approved as a 501(c)(3) organization by the IRS and your donations are tax deductible, where applicable.

Donations can be mailed to:

Fibrous Dysplasia Foundation
15 Browns Ct SE
Washington, DC 20003
info@fibrousdysplasia.org



Helping people worldwide

Improving the Quality of Life for Persons with Fibrous Dysplasia



Fibrous
Dysplasia
FOUNDATION

Helping people worldwide

What is Fibrous Dysplasia?

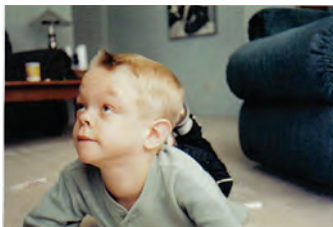
Fibrous Dysplasia (FD) is an uncommon bone disease caused by a defective gene in the cells that form bone. The cause of the gene defect is unknown, but it is neither inherited from one's parents, nor passed on to one's children. The gene defect can affect a single bone and go unnoticed for years, or it can affect virtually every bone, start very early in life, and result in significant physical impairment. Affected bones are weak and subject to fracture and deformity.

Surgery remains the mainstay of treatment for the long bones. Surgical treatment is complicated and is best performed by surgeons with experience with FD. In general, surgery in the bones of the skull is not medically required...because blindness and significant hearing loss are very uncommon, even though the nerves to the eyes and ears may be surrounded by FD.

What is McCune-Albright Syndrome?

Fibrous Dysplasia can be associated with birth marks (cafe-au-lait spots), and a number of endocrine problems such as precocious puberty (PP), hyperthyroidism, low blood phosphorus, excess growth hormone, and others. This is known as McCune-Albright syndrome. Rarely, other organ systems may be involved (liver, cardiac, parathyroid, pancreas).

FD and MAS often cause significant and chronic pain and pain management programs are needed. There is no cure for FD, but there are treatments for the various problems associated with it. Medications known as bisphosphonates (Aredia, Zometa, etc.) have been shown to be very effective in relieving pain.



What is Cherubism ?

With Cherubism, the solid bone in the lower part of the skull and jaw (maxilla and mandible) is replaced by fibrous tissue that is less dense, leading to swollen looking cheeks. Misplacement and loss of teeth (due to resorption of the roots) often occurs and can make eating difficult. In some cases, enlargement of the floor of the orbit (the bones surrounding the eye socket) also causes the eyeball to tip upward.

Cherubism, a painless condition, is usually first detected when the facial appearance of an affected child begins to look atypical. Due to others' reactions to their physical difference, people with Cherubism may feel isolated or insecure, adding an emotional impact to the condition, especially during adolescence and the teens.

Education:

The Fibrous Dysplasia Foundation provides information for the general public and medical professionals through a website: www.fibrousdysplasia.org. The website provides accessible descriptions of the clinical manifestations of Fibrous Dysplasia (FD), McCune Albright Syndrome (MAS), and Cherubism, frequently asked questions about the nature of FD and its treatment, and a library of medical articles. The FD Foundation provides, for a minimal fee, video recordings of medical practitioners presenting the cutting edge of research and clinical practice concerning FD and MAS in a format understandable by the general public.

FD Foundation board members attend national conferences for medical practitioners to build awareness of the services we provide to patients and caregivers and to solicit interest in the referral databank.

Support:

Because FD, MAS, Cherubism, and related conditions are rare, many individuals with these diagnoses negotiate the difficulties of these conditions

alone. These include pain management, treatment options, or social responses to their physical symptoms. Likewise, physicians assisting persons with these conditions may not develop an understanding of the broader concerns of affected individuals.

One means to build community among patients and among physicians is through electronic communication (as provided through the email exchanges on www.FDSOL.org). The FD Foundation annual conferences also bring together patients, families, and medical professionals for education and support.

Advocacy:

The Fibrous Dysplasia Foundation is focused on fundraising from individuals, corporations and the government in order to promote research into diagnoses, treatments and, ultimately, a cure for FD/MAS.

The FD Foundation is currently building the first comprehensive referral database of medical practitioners with expertise in the treatment of FD, MAS and Cherubism. This database will be searchable by medical specialty and geographic region.

Our Leadership:

The mission of the FD Foundation is carried out by volunteers across the nation who have FD, MAS and Cherubism, or care for someone affected by these conditions, under the direction of the Board of Directors. Board members are drawn from the general membership of the foundation and include accountants, teachers, lawyers, medical workers, primary parents, truck drivers, and marketing specialists who are committed to making our mission a reality.

The Medical Advisory Council assists the board by reviewing FD Foundation publications and helping establish research goals. This diverse advisory body includes doctors and researchers who are the experts from around the world for these rare diseases. For more information and/or a complete listing of the Board of Directors and Medical Advisory Council members see the FD Foundation website.

www.fibrousdysplasia.org

