

Directions to the Yawkey Center for Outpatient Care

From the North

- Take I-93 south to Exit 26 (Storrow Drive/Cambridge)
- Follow signs to Storrow Drive (stay left)
- Take Storrow Drive west to Government Center exit (left exit)
- At end of ramp, yield to crossing traffic at flashing traffic signal, then proceed straight
- Turn left onto Cambridge Street at traffic signal
- Turn left onto North Grove Street
- Follow signs to park at the Yawkey Center for Outpatient Care

From the South

- Take I-93 north to Exit 26 (Storrow Drive)
- Follow signs to Storrow Drive (stay right)
- Take Storrow Drive west to Government Center exit (left exit)
- At end of ramp, yield to crossing traffic at flashing traffic signal, then proceed straight
- Turn left onto Cambridge Street at traffic signal
- Turn left onto North Grove Street
- Follow signs to park at the Yawkey Center for Outpatient Care

From the West

- Take I-90 east to Exit 18 (Brighton/Cambridge)
- Follow signs to Cambridge/Somerville
- Turn right onto Storrow Drive eastbound to Downtown Boston
- Take Storrow Drive east to Government Center exit
- Follow signs to Downtown/Government Center (Cambridge St.)
- Turn left onto North Grove Street
- Follow signs to park at the Yawkey Center for Outpatient Care

From the East

- Take I-90 west through the Ted Williams Tunnel
- Follow I-90 west to Exit 24 (I-93 North)
- Take I-93 north to Exit 26 (Storrow Drive)
- Follow signs to Storrow Drive (stay right)
- Take Storrow Drive west to Government Center exit (left exit)
- At end of ramp, yield to crossing traffic at flashing traffic signal, then proceed straight
- Turn left onto Cambridge Street at traffic signal
- Turn left onto North Grove Street
- Follow signs to park at the Yawkey Center for Outpatient Care

Please pay for parking at the Cashier Desk in the Lobby.



Stickler Syndrome Clinic for Children and Adults



Mission statement:

The Stickler Syndrome Clinic will evaluate children and adults for whom the diagnosis of Stickler Syndrome has been raised and will coordinate multidisciplinary care for affected patients.

- MassGeneral Hospital/MassGeneral Hospital for Children
- Yawkey Center for Outpatient Care, Suite 6C, Boston, MA 02114
- Telephone: 617-726-1561
- Director: Ruth Liberfarb, M.D., Ph.D.
- Email: rilberfarb@partners.org
- Web site: http://massgeneral.org/children/specialtiesandservices/stickler_syndrome_clinic/default.aspx

Stickler Syndrome Facts

- First described by Stickler et al, 1965 & 1967
- Originally called Hereditary Progressive Arthro-ophthalmopathy
- Inheritance: Autosomal Dominant, Autosomal Recessive
- Prevalence: 1 in 10,000 – probably under diagnosed
- Penetrance: 100%
- Variable expressivity within a family
- Most common cause of hereditary Retinal Detachment
- Most common cause of juvenile Retinal Detachment
- Genetic heterogeneity
- Support group: Stickler Involved People (SIP) Email: sip@sticklers.org

Stickler Syndrome: Clinical features

- Ocular: Vitreoretinal degeneration, myopia, cataracts, retinal holes and detachments
- Auditory features: high tone sensory neural hearing loss, hypermobile tympanic membranes
- Craniofacial features: mid facial hypoplasia, micrognathia, palatal abnormalities (cleft palate, submucous cleft, bifid uvula, Pierre Robin anomalad)
- Musculoskeletal anomalies: mild spondyloepiphyseal dysplasia, loose joints, early onset degenerative arthritis
- Cardiovascular abnormality: mitral valve prolapse

Stickler Syndrome Clinic Evaluation

- Comprehensive family and medical history
- Physical examination
- Clinical tests (audiogram, echocardiogram, skeletal X-rays, and DNA analysis)
- Education/ genetic counseling
- Family Screening
- Reproductive options

Treatment of associated problems:

- corrective lenses; prophylactic laser or cryo retinal treatment; surgery; hearing aids; speech and feeding therapy; physical therapy and appropriate exercise; antiinflammatory and pain medication; referrals to specialists:
- Ophthalmologist or retina specialist
 - Evaluation needed at least annually or more frequently if medically indicated
- Audiologist – hearing evaluation is needed every 3-5 years
- Orthodontist – for a dental evaluation
- Rheumatologist or orthopedist – for musculoskeletal evaluation
- Physiatrist – for pain management
- Specialist in Reproductive Medicine and In Vitro Fertilization

This Brochure is funded by

Stickler Involved People
support group Website:

<http://www.sticklers.org/sip2/>

