Ehlers-Danlos Syndrome / Joint Hypermobility Syndrome

Are We Really Zebras, or Just Horses of Different Colors?

Heidi Collins, MD
Most medical professionals think EDS/JHS is exceedingly rare and exotic – a “Zebra”.

EDS/JHS is something most medical professionals do not expect to encounter.

- “I’ve heard of it. Never seen it before. We learned about it in medical school.” (said by a neurosurgeon to one of my patients with EDS/JHS)
- “It must be something else. I’ve been in practice 19 years, and I’ve seen everything. I’ve never seen a kid with that.” (said by a pediatric hospitalist to me, regarding POTS in my child with EDS/JHS)
“A horse of a different color metaphorically represents something that may be completely separate from what one originally expected. Frequently, a horse of a different color may be a complete surprise, an unexpected truth or a feature that seems somehow out of place.” (from “Idioms Unpacked”)
“Reports of the prevalence of [JHS] must be viewed cautiously because of the variability in the diagnostic criteria used. Hypermobility syndrome has been reported in 0.6% to 31.5% of adults without joint pain, depending on age, ethnicity, and criteria for assessing hypermobility.” (Russek LN. Hypermobility syndrome. *Phys Ther.* 1999;79:591–599.)
Prevalence: General Population

Table 2.
Prevalence of Hypermobility Syndrome Reported in the Literature for the General Population

<table>
<thead>
<tr>
<th>Male Subjects</th>
<th>Female Subjects</th>
<th>Total Subjects</th>
<th>Criteria Used</th>
<th>Age (y)</th>
<th>Population</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>%  N</td>
<td>%  N</td>
<td>%  N</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0.6 168</td>
<td>3.3 334</td>
<td>2.4 502</td>
<td>Brighton 6/9</td>
<td>20–82</td>
<td>Africans</td>
<td>Beighton et al¹⁸</td>
</tr>
<tr>
<td>1.0 104</td>
<td>2.9 104</td>
<td>1.9 208</td>
<td>Brighton 5/9</td>
<td>21–70</td>
<td>Caucasians</td>
<td>Wordsworth et al³⁹</td>
</tr>
<tr>
<td>2.8 422</td>
<td>8.9 214</td>
<td>4.9 636</td>
<td>Modified Carter-Wilkinson b 2/3</td>
<td></td>
<td>US adults</td>
<td>Jessee et al¹⁵</td>
</tr>
<tr>
<td></td>
<td>8.0 50</td>
<td></td>
<td>Brighton 3/5</td>
<td>50⁺</td>
<td>Patients without arthritis</td>
<td>Scott et al⁵³</td>
</tr>
<tr>
<td>6.7 134</td>
<td>18.3 126</td>
<td>12.3 260</td>
<td>Modified Beighton c</td>
<td>5–17</td>
<td>US school children</td>
<td>Gedalia et al³⁸</td>
</tr>
<tr>
<td>6.0 150</td>
<td>21.9 114</td>
<td>12.9 264</td>
<td>Brighton 5/9</td>
<td>15.5 avg</td>
<td>US adolescent athletes</td>
<td>Decoster et al⁴¹</td>
</tr>
<tr>
<td>6.9 360</td>
<td>33.7 300</td>
<td>19.1 660</td>
<td>Brighton 3/5</td>
<td>38.5 ± 11</td>
<td>Swedish factory workers</td>
<td>Larsson et al⁴⁵</td>
</tr>
<tr>
<td>23.6 1,187</td>
<td>31.5 587</td>
<td>29.8 1,774</td>
<td>Brighton [4–6]/9</td>
<td>20–24</td>
<td>US music students</td>
<td>Larsson et al³⁷</td>
</tr>
<tr>
<td></td>
<td>31.7 416</td>
<td>31.7 416</td>
<td>Carter-Wilkinson 5/9</td>
<td>5–17</td>
<td>Iraqi students</td>
<td>Al-Rawi et al³⁶</td>
</tr>
<tr>
<td>33.7 445</td>
<td>38.4 560</td>
<td>36.3 1,005</td>
<td>Carter-Wilkinson 5/9</td>
<td>5–17</td>
<td>Non-Caucasian Brazilian school children</td>
<td>Forleo et al⁴²</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Carter-Wilkinson 5/9</td>
<td>5–17</td>
<td>Caucasian Brazilian school children</td>
<td>Forleo et al⁴²</td>
</tr>
</tbody>
</table>

* “General population” refers to samples not selected because of joint pain or other medical conditions.

b Excluding dorsiflexion and knee hyperextension.

c Criteria as in Brighton et al¹⁸ except for hyperextension of fingers to lie parallel to forearm (as in Carter and Wilkinson¹⁹) rather than hyperextension of fifth metacarpophalangeal joint to 90 degrees.
Prevalence: Joint or Muscle Pain

### Table 3.
Prevalence of Hypermobility Syndrome Reported in the Literature for Populations Reporting Joint or Muscle Pain

<table>
<thead>
<tr>
<th>Male Subjects</th>
<th>Female Subjects</th>
<th>Total Subjects</th>
<th>Criteria Used</th>
<th>Age (y)</th>
<th>Population</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>% N</td>
<td>% N</td>
<td>% N</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.9 34</td>
<td>5.7 262</td>
<td>8.7 1311</td>
<td>Modified Beighton 3/5</td>
<td>5–17</td>
<td>Israeli school children with juvenile rheumatoid arthritis</td>
<td>Gedalia et al²¹</td>
</tr>
<tr>
<td></td>
<td>18.8 130</td>
<td>15.4 130</td>
<td>Beighton 3/5</td>
<td>NA</td>
<td>Patients seen in pediatric arthritis clinic</td>
<td>Biro et al²</td>
</tr>
<tr>
<td>8.7 1311</td>
<td>50.0 70</td>
<td>50.0 70</td>
<td>Beighton 3/5</td>
<td>3–70</td>
<td>Patients seen in rheumatology and rehabilitation clinics</td>
<td>el-Shahaly and el-Sherif⁵</td>
</tr>
<tr>
<td>0.0 33</td>
<td>20.6 97</td>
<td>15.4 130</td>
<td>Beighton 5/9</td>
<td>18–83</td>
<td>Patients with rheumatologic disorders</td>
<td>Bridges et al⁵¹</td>
</tr>
<tr>
<td>24.0 50</td>
<td>50.0 70</td>
<td>50.0 70</td>
<td>Beighton 5/9</td>
<td>50+</td>
<td>Patients with osteoarthritis</td>
<td>Scott et al⁵³</td>
</tr>
<tr>
<td></td>
<td>50.0 70</td>
<td>50.0 70</td>
<td>Beighton 5/9</td>
<td>NA</td>
<td>Patients with temporomandibular joint disease</td>
<td>Buckingham et al¹⁴</td>
</tr>
<tr>
<td>56.8 37</td>
<td>68.7 67</td>
<td>64.4 104</td>
<td>Modified⁴ Carter-Wilkinson 3/3</td>
<td>12–47</td>
<td>Patients with patellar dislocation</td>
<td>Grahame⁴</td>
</tr>
<tr>
<td>30.0 10</td>
<td>66.5 200</td>
<td>64.8 210</td>
<td>Beighton 3/5</td>
<td>21–78</td>
<td>US patients with fibromyalgia</td>
<td>Goldman⁶⁸</td>
</tr>
<tr>
<td></td>
<td>65.6 32</td>
<td>55.0 32</td>
<td>Modified Beighton 3/5</td>
<td>5–17</td>
<td>US school children with juvenile episodic arthritis/arthralgia</td>
<td>Gedalia et al¹³⁸</td>
</tr>
<tr>
<td></td>
<td>81.0 21</td>
<td>81.0 21</td>
<td>Modified Beighton 3/5</td>
<td>9–15</td>
<td>Israeli school children with fibromyalgia</td>
<td>Gedalia et al²¹</td>
</tr>
</tbody>
</table>

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¹⁵/15 subjects were diagnosed with juvenile arthritis, leaving 12/262 or 4.6% with primary hypermobility syndrome.

² Criteria as in Beighton et al,¹⁸ except for hyperextension of fingers to lie parallel to forearm (as in Carter and Wilkinson¹⁹) rather than hyperextension of fifth metacarpophalangeal joint to 90 degrees.

³ Original report used Beighton 4/9 as the cutoff. To allow comparison with other reports using Beighton 5/9 criteria, percentages were recomputed using raw data reported.

⁴ Including only tests of hyperextension of elbows and knees, apposition of thumb to forearm.

⁵ Specified that hypermobility needed to be present in bilateral elbows or knees to score on either criterion.

⁶ Excluded children with juvenile rheumatoid arthritis.
Why do I care about this topic?

- I am a person with EDS/JHS.
- I am a medical professional.
- I believe both patients and medical professionals need to understand EDS/JHS as something that may be *unexpected* but is *not so rare and exotic*!
- I believe EDS/JHS patients and medical professionals need to have reasonable expectations of one another.
Our Responsibilities
As Persons with EDS/JHS

- Use every resource available to educate ourselves about EDS/JHS.
- Learn how to prioritize treatment goals.
- Learn to advocate effectively for the best medical care.
- Educate others (medical professionals, family members, friends, schools, employers, etc.) regarding EDS/JHS.
Our Responsibilities
As Medical Professionals

- **Diagnose:** Recognize EDS/JHS and differentiate it from other “less rare and exotic” conditions.
- **Treat:** Address the difficulties experienced by EDS/JHS patients.
- **Counsel and Educate**
- **Research: An Ongoing Process**
  - Strive to understand EDS/JHS and related disorders.
  - Continually refine and update the standard of care for patients with EDS/JHS and associated connective tissue disorders.
  - Identify specific opportunities for impact in individual specialties.
  - Identify areas deserving further research.
- **Continue to integrate emerging knowledge into everyday practice.** (Continuing Medical Education)
Especially, why is it so hard for an EDS/JHS patient to get diagnosed?

It has to do with how medical professionals are trained to diagnose.
The Zebra Aphorism: History

- "When you hear hoofbeats, think horses, not zebras." (Theodore E. Woodward, MD, University of Maryland, circa 1950)

- Earlier Versions:
  - “When you hear hoofbeats behind you, don't expect to see a zebra.”
  - “Don't look for zebras on Greene Street.”
“The striking and novel stay longer in the mind.” (Rhetorica ad Herennium, 85 BC)
“Events more easily remembered are judged more probable.” (The Availability Heuristic)
So that rare disorders are not overdiagnosed, it is important to resist the tendency to assign rare diagnoses; instead, remember to consider most probable causes or conditions first.
The Zebra Aphorism: For Novices Only

- **Meant for medical novices, not experienced medical professionals!**
  - Medical Student Syndrome (see http://medicalstudentsyndrome.com/)
    - Not limited to medical students.
    - Anyone who reads medical literature is susceptible!
  - Medical Students’ Disease (see Wikipedia)

- **When overused among fully trained professionals, the Zebra Aphorism leads to unwarranted skepticism regarding acceptance of rare diagnoses when they actually occur.**
Ockham’s Razor: Keeping it Simple

- Sometimes stated as: “The simplest explanation is usually the best.” (William of Ockham, fourteenth century English logician and Franciscan friar)
- Stresses keeping theories as simple as possible, with as few assumptions as possible.
  - "Entities should not be multiplied beyond necessity.” (Latin, as “lex parsimoniae”)
  - “Simplicity is the ultimate sophistication.” (Leonardo da Vinci)
  - “Theories should be as simple as possible, but no simpler.” (Albert Einstein)
  - “Keep It Simple, Stupid!” (The KISS Principle)
- In modern medicine, this is known as “Diagnostic Parsimony”: Strive to look for the fewest possible diagnoses (ideally a singular diagnosis) to explain symptoms and findings.
Hickam’s Dictum: Adds Balance to Ockham’s Razor

“Patients can have as many diseases as they damn well please.” (John Hickam, MD., Duke University, circa 1950)

Often, it is statistically more likely that a patient has several common diseases rather than a single rare disease.

Furthermore, even when statistically unlikely, patients can prove to have multiple diseases.
“In making the diagnosis of the cause of illness in an individual case, calculations of probability have no meaning. The pertinent question is whether the disease is present or not. Whether it is rare or common does not change the odds in a single patient. ...If the diagnosis can be made on the basis of specific criteria, then these criteria are either fulfilled or not fulfilled.” (A. McGhee Harvey, James Bordley II, Jeremiah Barondness)
The EDS/JHS diagnostic experience can be crushing!

- Ever feel like you’ve been told:
  - “You’re a horse. Shut up and eat your hay!”
- Ever been accused of doctor shopping?
- Ever been accused of having an agenda?
- Variations on a theme:
  - “But you don’t look sick.”
  - “Are you faking/crazy?”
- How many costly or painful tests came back “negative” or “normal”?
- How long is your list of diagnoses?
The Journey to Diagnosis

- **How Much Time: Weeks? Months? Years?**
  - Lengthy Referral Processes
  - Long Waits for Appointments

- **How Much Money?**
  - Medical Expenses
  - Travel Expenses
  - Treatments Not Covered by Insurance
  - Lost Income, etc.

- **How Many Stops/Detours/Dead Ends?**
  - How useful was each medical professional?
  - How many along the way? 10? 20? More?
The Journey to Diagnosis: Valid Questions from Patients

- Should physicians be expected to recognize every rare or uncommon disease “in the book”?
- How much does a typical medical professional know or recall about connective tissue disorders?
The Journey to Diagnosis: Valid Answers from Professionals

- I don’t know.
- I will look it up.
- I will find someone else who does know.
The Journey to Diagnosis: Diagnostic Standards Have Evolved

1964: Carter & Wilkinson Scoring System

1967: “The Hypermobility Syndrome”

1973: Beighton Scoring System

1973: Beighton Scoring System

1988: Berlin Nosology

1992: Bulbena Criteria

1993: Mosaic, the First Web Browser

1994: WebCrawler, one of the First “Full Text” Web Search Engines

~1995: “POTS”

1996: Ghent Nosology

1998: Villefranche Nosology

1998: Revised Brighton Diagnostic Criteria

2000: Revised Ghent Nosology for the Marfan Syndrome
Taking Matters into Your Own Hands

- **Web as Medical Consultant**
- **Official Medical Resources**
  - Texts
  - Journals
  - Other (e.g. Web Sites, Podcasts, Official Transcripts or Recordings of Medical Presentations, PowerPoint Presentations, etc.)

- **Patient-Based Resources**
  - Blogs
  - Forums
  - Social Media
  - Other (Web Sites, YouTube, Smartphone Apps, etc.)
Strength in Numbers: Horton Hears a Who!

- A voice previously unheard gains strength in numbers.
- Whether EDS/JHS is “rare” or “uncommon”, numbers like 1 in 200,000 or >1 in 100 matter little anymore.
- Modern technology has allowed patients to find one another and be heard.

“A person’s a person no matter how small!”
Smackdown!
Smackdown!

When they are correct in self-diagnosis, patients all too often are dismissed by medical professionals.

- “That’s not even a real condition.”
- “No, you can’t have that. It’s just too rare.”
- “Well, I suppose it’s possible, but I don’t know anything about that, so let’s stick to something I DO know.”

Don’t go down for the count!!!
Even when an EDS/JHS “zebra” is finally recognized, whether diagnosed by a knowledgeable medical professional or through self-diagnosis and self-advocacy, the journey is not over.
Baggage:
Re-Packing for the Rest of the Journey
Once diagnosed, in order to set priorities for treatment goals, medical professionals must help patients with their “baggage”.

The List of Diagnoses EDS/JHS Patients Carry

- Is each diagnosis primary or secondary?
  - Better control of primary problems can lessen secondary problems.
- What are the overlapping diagnoses?
  - Realize when successful treatment of one problem may not alleviate symptoms altogether.
- Can any diagnoses be struck from the list?
  - Fibromyalgia, Chronic Fatigue, Paroxysmal Atrial Tachycardia, Inappropriate Sinus Tachycardia, Panic Attacks, Anxiety, etc.
  - Especially true for “Diagnosis of Exclusion”.

LESS IS MORE!!!
The Next Part of the Journey: Treatment

- It is reasonable for a patient to expect that a medical professional can provide or arrange treatment for EDS/JHS.

- For some EDS/JHS patients:
  - This expectation is not met.
  - This expectation is met, but with great difficulty.

- Treatment of EDS/JHS may be challenging, but it should not be considered impossible!
At present, EDS/JHS is not well-known by the average medical professional.
Why is EDS/JHS not well-known by the average medical professional?

- For some, it was long ago forgotten.
  - They skipped that chapter in medical school.
  - They got enough of the other questions right to pass.
- The Zebra Aphorism gets overused.
- No singular diagnostic test is available.
  - Laboratory: Blood, Urine, Biopsy, Fibroblast Culture, etc.
  - Imaging: X-ray, MRI, Ultrasound, etc.
- Established scores and criteria help, however…
  - Lack of Awareness
  - Potential Difficulties with Interobserver Reliability
  - Subjectivity
- No definitive pharmacological or surgical treatment exists.
  - Why look for it if I can’t do anything about it?
Additional Findings in Patients with Hypermobile Joints: When EDS/JHS Should be on the Radar (A Partial List)

- **Emergency Physicians, Surgeons**
  - Bruises and Dislocations: Not Always Abuse
  - Vascular Rupture: Ritter Rules
  - Platelet Aggregation Failure

- **Pediatrics**
  - Earlier diagnosis means earlier intervention!

- **Family Practice, Internal Medicine Physicians**
  - Exhaustion/Fatigue
  - Diffuse Pain

- **Rheumatologists, Orthopedists, Physiatrists, Physical and Occupational Therapists**
  - Many can’t see the forest for the trees.

- **Cardiologists**
  - Dysautonomia: POTS, NCS, NMH, OI
  - MVP
  - Aortic Dilatation

- **Pulmonologists**
  - Tracheo/bronchomalacia
  - Tracheo/bronchomegaly
  - Chronic Cough
  - Refractory “Asthma” or “COPD”
  - Impaired Gas Exchange
  - Pectus Deformities

- **Sleep Specialists**
  - Refractory Insomnia
  - Frequent Paroxysmal Arousals
  - Sleep Disordered Breathing
  - Upper Airway Resistance Syndrome
  - Nocturia

- **Psychiatrists, Psychologists, Neurologists**
  - Anxiety, Panic
  - ADD Inattentive
  - Social Phobia
  - When Considering Autism/ASD
  - Migraines

- **Gastroenterologists**
  - IBS
  - Esophageal or Other Gut Dysmotility
  - Constipation
  - Abdominal Pain on Standing
  - Dysbiosis

- **Anesthesiologists**
  - Local Anesthesia Considerations
  - General Anesthesia Considerations
  - Dural Ectasia

- **Neurosurgeons**
  - Occipitoatlantoaxial Hypermobility
  - Chiari Malformation
  - Tethered Cord
  - Intracranial Pressure Abnormalities
  - Spontaneous CSF Leaks

- **ObGyns**
  - Cervical Incompetence
  - Early Rupture
  - Precipitous Delivery
  - Peripartum Hemorrhage
  - Endometriosis
  - Irregular/painful Menses
Additional Findings in Patients with Hypermobile Joints: When EDS/JHS Should be on the Radar (A Partial List)

- **Dermatologists**
  - Lax Skin, “Stretch Marks”
  - Scarring: Atrophic, Papyraceous
  - Keratosis Pilaris
  - Molluscoid Pseudotumors

- **Ophthalmologists**
  - Myopia, etc.
  - Lens Displacement
  - Blue Sclera
  - Vitreal Abnormalities (e.g., “Floaters”)

- **ENTs**
  - Hearing Loss
  - Tinnitus/Hyperacusis
  - Macroglossia
  - Gorlin’s Sign
  - Bifid Uvula
  - Laryngotrabichal Reflux

- **Dentists, Orthodontists**
  - Palate Involvement
  - Crowding
  - Dental Fracture
  - Gingival Problems
  - Need for “Excessive” Anesthesia
  - Rapid Corrrection with Orthodontia

- **Speech and Language Pathologists**
  - Dysphonia
  - Dysarthria
  - Dysphagia

- **Allergists/Immunologists**
  - Food Intolerance
  - Hypersensitivity
  - MCAD
  - Immune Dysregulation
A considerable body of knowledge regarding the diagnosis and treatment of EDS/JHS does exist.

When this knowledge is put into practice, patients can gain/regain significant health and functionality.

The body of knowledge has grown, especially in recent years, and will continue to grow.

This underscores the importance of organizations like EDNF.

- Resources are readily available on the EDNF Web Site.
  - Medical Literature
  - Contact Information for Other Medical Professionals
  - Newsletters

No Excuses!

- Medical professionals must make a reasonable effort to gain the knowledge they need to benefit their patients!
When modern practitioners feel limited by their own knowledge or their local resources, they need to learn to navigate the Web as an easily accessible means of continuing their own medical education and connecting patients with capable or experienced medical professionals, official organizations, educational resources, and other means of support!!!
The Web: Words of Caution

- The Web DOES NOT eliminate the need for face-to-face patient-physician interaction.
- Information from the Web should be discussed between patients and medical professionals.
- Patients need help recognizing whether information is from a valid, credible source.
- Medical professionals must not disregard information solely because a patient found it while surfing the Web.
- Medical professionals must verify the credibility of information before integrating it into practice.
- The Web is a magnificent tool for self-education for both patients and practitioners, ***HOWEVER*** it has its pros and cons, and information from the web needs to be utilized in an APPROPRIATE fashion.
The Web: Words of Caution

Un médecin suisse explique que Michael Jackson souffrait du syndrome d’Ehlers-Danlos

MALADIE RARE | La doctoresse fribourgeoise Scarlet Huissoud pense que Michael Jackson souffrait du syndrome d’Ehlers-Danlos. Cette maladie souvent méconnue se caractérise par une souplesse extrême et des douleurs intolérables. La police traite ce décès comme un homicide. L’enquête se concentre sur le médecin personnel de la star.

© Eyedea Presse/1988 | Beaucoup de détails font penser que Michael Jackson aurait pu souffrir du syndrome d’Ehlers-Danlos. C’est une remarque anodine d’un collègue sur le fait que la star à la souplesse époustouflante dansait sur les talons qui a fait tilt chez le Dr Huissoud.
A Swiss doctor explains that Michael Jackson suffered from Ehlers-Danlos Syndrome

RARE DISEASE | The doctor Fribourg Scarlet Huissoud think Michael Jackson was suffering from Ehlers-Danlos syndrome. This disease often overlooked is characterized by extreme flexibility and unbearable pain. The police are treating the death as a homicide. The survey focuses on the medical staff of the star.

© Eyedea Presse/1988 | Many details suggest that Michael Jackson might have suffered from Ehlers-Danlos syndrome. It's a casual remark from a colleague on the fact that the star with the flexibility breathtaking dancing on the heels that made tilt at Dr. Huissoud.
The Web: Words of Caution

When surfing the Web, there is no lifeguard on duty.

Regarding Web-based information, ask yourself:

Fact?
Fiction?
  Misinformation
  Urban Myths
Speculation?
In Conclusion

- EDS/JHS is NOT exceedingly rare.
- As a person with EDS/JHS, I do not think of myself as a zebra!
- I am just a horse of a different color.
- Now, if I could just get more than a handful of my fellow medical professionals to tell the difference between zebras and horses...
Last but not Least...
Useful Links

  EDS Hypermobility: http://www.ncbi.nlm.nih.gov/books/NBK1279/

Online Mendelian Inheritance in Man: http://www.omim.org/
  EDS Classic: http://www.omim.org/entry/130000
  EDS Hypermobility: http://www.omim.org/entry/130020
  EDS Vascular: http://www.omim.org/entry/130050

eMedicine: http://emedicine.medscape.com/
Useful Links

Ehlers Danlos, Joint Hypermobility, etc.
http://ednf.org/
http://www.ehlers-danlos.org/
http://www.ehlersdanlosnetwork.org/
http://www.hypermobility.org/
http://www.loeysdietz.org/
http://claude.hamonet.free.fr/eng/home.htm
http://claude.hamonet.free.fr/eng/art_sed.htm
http://claude.hamonet.free.fr/fr/art_sed.htm

Dysautonomia and POTS, etc.
http://www.dysautonomiainternational.org/
http://www.dynakids.org/
http://www.ndrf.org/
http://www.potsuk.org/
http://www.potsplace.com/

Pulmonary/Sleep Issues: Tracheobronchomalacia/Tracheobronchomegaly, Chronic Cough, Upper Airway Resistance Syndrome, and Insomnia
http://www.medcyclopedia.com/library/topics/volume_ii/t/tracheobronchomegaly.aspx
http://www.theasthmacenter.org/index.php/disease_information/asthma/related_conditions/tracheobronchomalacia/
http://chestjournal.chestpubs.org/content/127/3/984.full.pdf
http://chestjournal.chestpubs.org/content/129/1_suppl/206S.full.pdf
http://ajrccm.atsjournals.org/cgi/reprint/164/7/1242
http://jp.physoc.org/content/551/3/1043.full.pdf
Useful Links

**Wikipedia**

**Useful PDFs**
- See http://dynakids.org/awareness.jsp Dysautonomia Awareness Brochures:
  - Youths, College Students, Parents, Friends, Physicians, Teachers