

5th Annual Ullrich/Bethlem Patient and Family Meeting

August 9, 2008

8:30 am	Breakfast	
9:00 am	Welcome Clinical Manifestations	Carsten Bönnemann, M.D.
	The Hammersmith Experience	Amelie Nadeau, M.D.
9:30 am	CHOP CoPS Update	Reghan Foley, M.D.
10:00 am	Upper extremity function	Tim Estilow, OT
10:30 am	Break	
10:45 am	Contractures and Wheelchairs	Allan Glanzman, PT
11:15 am	Potential Innovations for Function	Mijail Serruya, M.D., Ph.D.
11:30 am	Nutrition: Promoting Bone Health Dexa Scans and More	Maria Hanna, MS, RD, LDN Donna DiVito, RD, CNSD
12:00 pm	Lunch	
1:00 pm	Orthopedics Overview: Focus on Contractures and Hip Dislocations	David Spiegel, M.D.
1:30 pm	Pulmonary Overview: Promoting Function and Preventing Infections	Robert Heinle, M.D.
2:00 pm	Our Current Understanding of the Collagen VI Myopathies Perspectives for Clinical Trials Other Treatment Approaches	Carsten Bönnemann, M.D.
3:00 pm	Break	
3:15 pm	Cure CMD Campaign	Anne Rudkowski, M.D.
3:45 pm	Discussion about Conferences and Advocacy	Carsten Bönnemann, M.D.
4:30 pm	Transition into Adulthood	Simon Cantos, BSME Alan Tuttle, MS
5:00 pm	Good-Bye and Pictures	UCMD/BM All-Star Team



The Children's Hospital
of Philadelphia
Division of Neurology



Neuromuscular
Research Lab
at CHOP

Collagen VI Related Myopathies: Exploring the Phenotypic Spectrum

A. Reghan Foley, M.D.

Collagen VI is a protein in the extracellular matrix of muscle tissue that helps to maintain the integrity and survival of muscle fibers. Ullrich congenital muscular dystrophy (UCMD) is caused by either autosomal recessive or dominant mutations in the genes coding for collagen VI (*COL6A1*, *COL6A2*, *COL6A3*) and is characterized by a combination of early-onset muscle weakness, congenital contractures of proximal joints, and hyperlaxity of distal joints. Bethlem myopathy (BM) is caused by autosomal dominant mutations in *COL6A1*, *COL6A2*, or *COL6A3* and is a more benign, slowly progressive myopathy with typical flexion contractures of the fingers, wrists, elbows, and ankles. Certain collagen VI mutations have been found to be present both in patients with mild UCMD and patients with severe BM, raising the question of a continuous clinical spectrum between UCMD and BM.

Methods: A survey analyzing the phenotypes of UCMD and BM patients (*CHOP CoPS*-The Children's Hospital of Philadelphia Collagen VI Deficiency Patient Survey) was mailed to U.S. patients with genetically confirmed diagnoses of UCMD or BM (n=39). (Complete UCMD/BM cohort totals 57 patients.) Sixty-eight questions regarding details of phenotype, quality of life, and clinical trials were included.

Results: Completed surveys (n=16) were analyzed for preliminary trends. While the classic phenotypes of UCMD and BM were identified, also identified were patients demonstrating varying phenotypic severity within a highly variable constellation of individual symptoms, thus pointing toward a spectrum disorder of collagen VI related myopathies connecting the two classic phenotypes of UCMD and BM. UCMD patients appear prone to easy fractures, which has not been previously described.

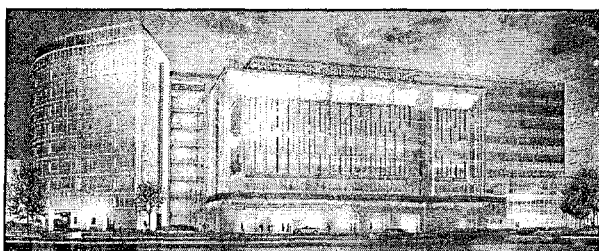
Comprehensive definitions of phenotypic aspects of UCMD and BM are important in the development of inclusion criteria, exclusion criteria, and outcome measures for a Phase II clinical trial for patients with UCMD and BM scheduled to begin at CHOP in 2009.

Notes: _____

OCCUPATIONAL THERAPY

- Occupational Therapy's role in the treatment of patients with UCMD/BM
- Assistive devices
- Environmental modifications
- Therapeutic activities.
- CONTACT INFORMATION:
 - Tim Estilow, OT estilow@email.chop.edu (215) 590-7655

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DXA & Bone Health

Maria Hanna, MS, RD, LDN

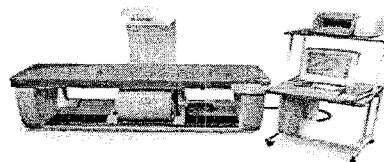
Program Coordinator

Center for Bone Health

The Children's Hospital of Philadelphia

The DXA machine

Dual Energy Xray Absorptiometry



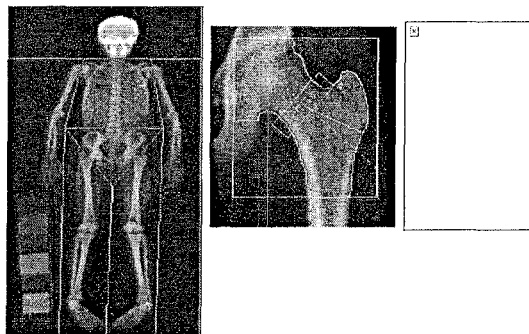
* Widely available (100,000 DXA's)

Why DXA?

- DXA is a rapid, noninvasive tool
 - Spine/hip scan in 30 seconds, whole body in 3 minutes
 - Assesses presence of bone loss by measuring:
 - BMC = Bone Mineral Content
 - BMD = Bone Mineral Density
- Safe, easily tolerated, very low radiation exposure:
 - (1/100th of a dental film)
 - No shielding required
- Can assess bone density at different skeletal sites: WB, spine, hip, forearm, femur

DXA

(dual energy x-ray absorptiometry)

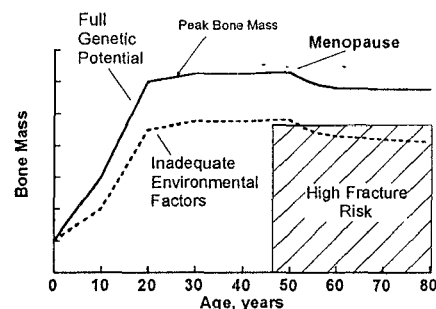


Why do this on kids?

For years, DXA was used primarily in the postmenopausal population. However, many diseases and medications put the pediatric patient at risk.

- Inflammation: IBD, Celiac, CF, JRA
- Short gut
- Transplant
- Epilepsy
- Cerebral Palsy
- Neuromuscular

Life Cycle Changes in Bone Mass



NIH Osteoporosis Consensus Conference Statement

- Concluded that *"Bone mineral accretion during childhood is a critical determinant of the risk of osteoporosis later in life."* (March 2000)
- *Bone fragility* influenced by bone mass, density, geometry, micro-repair

Factors Influencing Development of Osteoporosis

- | | |
|------------------------------------|------------------------------------|
| - Body size | - Genetic factors |
| - Nutritional Status | - Ethnicity |
| - Dietary intake | - Overall Health |
| - Weight-bearing physical activity | - Medications |
| - Smoking | - Postmenopausal rate of bone loss |
| - Peak bone mass | |

CHOP Indications for DXA

Age 4* y or older with:

- Abnormal bone density on plain radiograph
- History of fractures
- Use of medications that adversely affect bone health
 - Steroids > 6 months; Anticonvulsants (phenobarb)
- Malnutrition; Stunting of linear growth
- Fat malabsorption
- Other chronic diseases (e.g., Liver / renal disease)
- Family history of osteoporosis
- Decreased physical activity
- Vitamin D deficiency or insufficiency
- Lactose intolerance or inadequate calcium intake

*No normative data for younger age

DXA at CHOP

- Four trained RNs: performed over 700 scans 07-08
- Includes anthropometrics, Tanner staging, BMI.
- Parents and patients are interviewed to assess health history as it relates to their bones:
 - Diet, Meds, Vitamin & Calcium Supplements
 - Fracture history
 - Activity Level/Exercise
- Interpreted by trained pediatric nutrition specialists, one is ISCD* certified

» *The International Society for Clinical Densitometry

Test Preparation

- Hold calcium supplements the day of the test
- No radioopaque contrast (includes barium, nuclear med isotopes, CT contrast) within 7 days of scan
- Dressed in clothing free of metal, no piercings, no jewelry (will falsely elevate density)
- Patients 7-17yo with spinal rods can now have forearm scan

Z Score



- the only value used to determine BMD in children
- age matched
- is the number of standard deviations from the mean

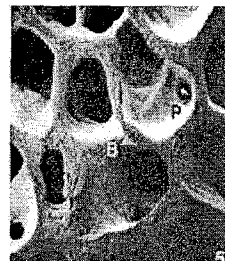
T score



- Is used in adults and compares to peak bone mass reached at mid to late 20s.
- Not to be used with children (They are still building their bones!)
- Beware: Some adult facilities without pediatric software may report it as osteoporosis

So what's a normal DXA?

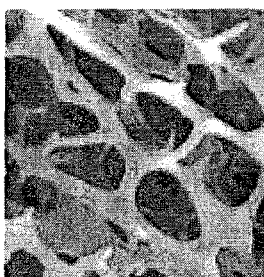
- Z-score of -1 SD or greater
- Meshwork of the bone is tightly woven and more resistant to force



Normal Bone

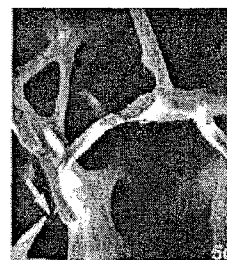
What's Osteopenia?

- Z-score between -1 and -2.5 SD in adults
- Meshwork of the bone is beginning to thin



What's Osteoporosis?

- Z-score less than -2.5 in adults and yields an increased fracture risk
- Note how bone appears "lacy" - prone to fracture



Osteoporotic Bone

CALCIUM ROCKS!

- Calcium, from the diet and/or supplements, is part of the first line of treatment for low bone density.
- CHOP report has MD recommendations:
 - Based on age
 - Max = 2500 mg/day
 - Factors to consider: high protein diets, vitamin C supplementation, risk of renal stones, malabsorption

Recommended Calcium Intake		
AGE	DAILY INTAKE	GLASSES OF MILK
1-3	500 mg	1½
4-8	800 mg	2½
9-18	1300 mg	4½
19-50	1000 mg	3½
51+	1200 mg	4

Food Sources of Calcium

- Best sources: dairy, especially milk, yogurt and cheese
- Other: nuts, legumes, greens, oranges, figs
- Fortified OJ, soy and rice milks
- Fortified cereals and waffles.



Calcium Supplement Basics

- Pill, chewable and liquid forms are available
- Most forms should be taken with meal
- Antibiotics and Iron can interfere with absorption
- Common forms are carbonate and citrate. Studies have shown absorption levels of 20-40%, respectively.
- Should NOT take more than 500 mg at a time



Vitamin D

- Few foods have it
- Best sources: the sun and Vitamin D supplements
- Assess and Monitor via Vitamin D-25-OH level

Vitamin D Metabolism

- Sunlight/UVB → precursor converted to → Vitamin D3 = cholecalciferol → translocated to skin
- Diet or Supplement:
 - D2 = Ergocalciferol = plant sources (yeasts, plants)
 - D3 = Cholecalciferol = animal sources

Vitamin D

- Fat soluble vitamin that is key to calcium absorption and balance
- Likely to have other effects related to muscle and immune function
- Vitamin D insufficiency is common

Symptoms of Vitamin D Deficiency

- Usually asymptomatic
- Osteomalacia - vague symptoms of:
 - Bone pain, achiness
 - Muscular weakness
 - Feeling of heaviness in the legs
 - Chronic musculoskeletal pain
 - Fatigue, easy tiring

Vitamin D Deficiency has also been Associated with:

- | | |
|--------------------------|--|
| • Cancer | • Periodontal disease |
| • Cardiovascular disease | • Macular degeneration |
| • Hypertension | • Depression |
| • Stroke | • Propensity to fall |
| • Diabetes | • Influenza/other winter-time infections |
| • Multiple Sclerosis | • Autism |
| • Rheumatoid Arthritis | |
| • IBD | |

“What is the ideal Vitamin D-25-OH level”?

- $\geq 15\text{ng/ml}$: prevent rickets & osteomalacia
- $20\text{-}30\text{ng/ml}$: suppress PTH levels
- 34ng/ml : optimize intestinal calcium absorption
- 38ng/ml : peak performance in athletes; reduce incidence of internal cancers
- 52ng/ml : decrease incidence breast cancer by 50%
- $50\text{-}70\text{ng/ml}$: natural levels for those who live or work in the sun

» Cannell et al., Expert Opin.Pharmacother. (2008)9(1)

Factors affecting Vitamin D levels

- Latitude
- Season
- Time of day
- Air pollution
- Cloud cover
- Use of sunblock
- Meds such as:
Anticonvulsants,
corticosteroids
- Age
- Obesity
- Skin Melanin content
- Extent of clothing covering the body
- Glass windows (home/cars)
- Smoking

Treatment of Vitamin D Deficiency

- Cholecalciferol = Vitamin D3
- Amount needed varies with:
 - Body weight
 - Body fat
 - Skin color
 - Season
 - Latitude
 - Sunning/Tanning Habits

Recommendations for Vitamin D3 supplementation

- Vitamin D Council – general population
- Periodic monitoring [25(OH)D] and calcium levels
 - Treat levels $< 40\text{ng/mL}$; goal = $40\text{-}65\text{ng/mL}$
 - Physiological doses: $4,000\text{-}10,000\text{ IU/day}$ from all sources
 - Goals: prevent metabolic bone disease and other Vitamin-D deficiency associated ones

» www.vitamindcouncil.org/treatment.shtml

Cholecalciferol = Vitamin D3

- Why Choose D3?
 - Longer half-life
 - Maintains [25-(OH)-D] longer
 - More potent (3-10x) → need lower dosage
- Concerns:
 - Finding reliable high dose D3 supplements
 - ?Cost (OTC – no insurance coverage)
 - ?Toxicity:
 - Excessive ingestion: $> 5000\text{-}10,000\text{ IU/day}$ for many months
 - Mostly very high blood levels of 25(OH)D $>125\text{-}150\text{ng/mL}$

Sunlight and Latitude

- ✳ Above $\sim 40^\circ\text{N}$ and below $\sim 40^\circ\text{S}$
 - No vitamin D3 synthesis in the skin for 3-4 months of winter (Nov – Feb)
 - Boston = 42°N ; Milwaukee = 43°N
- ✳ Far northern and southern latitudes
 - No vitamin D3 synthesis in the skin for ~ 6 months of winter (Oct – Mar)
 - Edmonton, Canada = 52°N

Sunlight and Latitude, cont.

☼ Exposure at Lower Latitudes:

- Vitamin D3 synthesis the entire year
- Los Angeles, 34°N; Puerto Rico, 18°N
- Buenos Aires, 34°S

☼ Excess production during Spring, Summer and Fall → stored at fat and used during Winter

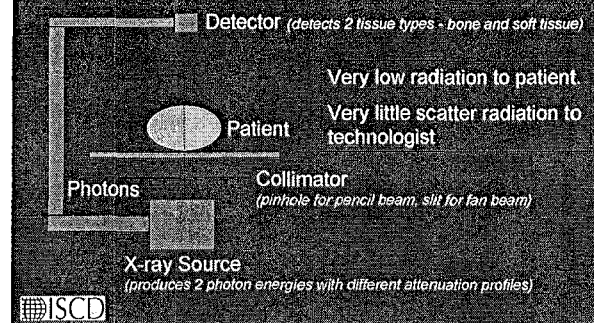
Biphosphonates

- Anti resorptive: slows down bone removal
- Complex dosing regimen of oral form
- Causes GI irritation
- Not FDA approved in kids
- Used infrequently: usually setting of fractures; under guidance of experts (endocrine, metabolism)
- Long term effects on kids and growing bone not yet known

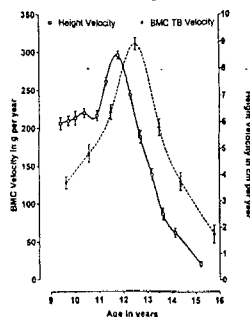
Follow Up at CHOP

- We repeat DXA scan every 6 months to 2 years, depending on results.
- Further evaluation and treatment at Center for Bone Health:
 - Multidisciplinary Bone Health Clinic
 - 3 pediatric physicians with research and/or clinical experience
 - Registered Dietitian and Physical Therapist

DXA Technology



Critical Period for Bone Mineral Accrual



Bone basics

- Cortical bone makes up the shafts of long bones. Only 3% of this bone is renewed yearly
- Trabecular bone makes up the inner bone, located mostly in the spine. 25% is renewed each year
- Osteoclasts remove old bone (clasts/chew)
- Osteoblasts produce new bone (blasts/build)
- Bone loss occurs when resorption exceeds formation

Z-scores and delayed bone or pubertal age

We do not make routine adjustments for this. Our standard is to use chronologic age, as any illness that has impacted growth has also likely impacted bone health.

Threats to Bone Structure

Decreased Formation

- Malnutrition
- Malabsorption
- Glucocorticoids
- Delayed puberty
- Decreased activity
- Reduced muscle mass

Increased Resorption

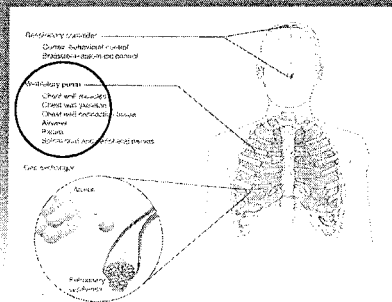
- Cyclosporine
- Increased PTH
 - Low Vitamin D level
- Cytokines

Pulmonary Overview: Promoting Function and Preventing Infections

Robert A. Heinle, MD
Pulmonary Division
Nemours at A.I. duPont Hospital for Children

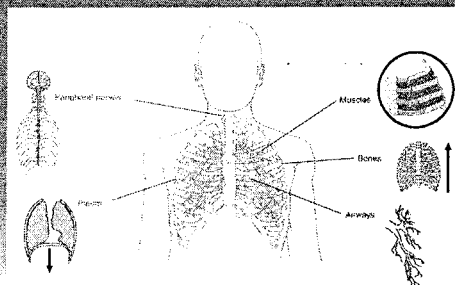
Nemours Alfred I. duPont
Hospital for Children
Nemours
Children's Clinic

General Pulmonary Mechanics



Nemours Alfred I. duPont Hospital for Children

General Pulmonary Mechanics – In Health



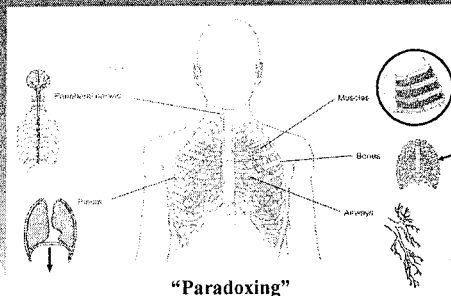
Nemours Alfred I. duPont Hospital for Children

General Pulmonary Mechanics

- Other Respiratory Maneuvers
 - Sigh
 - Fully expands the lungs
 - Opens distant air sacs preventing collapse (balloon analogy)
 - Ambulation
 - Promotes deep breathing, expanding lungs
 - Vibrations help mucociliary ladder clear secretions
 - Repositions dependent areas of lung that are prone to collapse and collection of secretions
 - Cough
 - Clears airway of secretions
 - Prevents pneumonia

NeuroGen
Effect of nerve
impairment on
respiration

Impact of Neuromuscular Weakness



NeuroGen
Effect of nerve
impairment on
respiration

Impact of Neuromuscular Weakness

- Other Respiratory Maneuvers
 - Sigh — decreased strength to expand the lungs fully predisposes distant air sacs to collapse
 - Decreased Ambulation
 - Less deep breathing and lung expansion
 - Less assistance to the mucociliary ladder
 - Consistent dependent areas of lung become prone to collapse and collection of secretions
 - Ineffective Cough
 - Predisposes to buildup of secretions/pneumonia

NeuroGen
Effect of nerve
impairment on
respiration

Impact of Neuromuscular Weakness

- Cough Mechanics
 - Inspiratory phase
 - Expands lungs to 80-90% of total lung capacity
 - Allows air to pass beyond/behind secretions
 - Compressive phase
 - Voice box closes
 - Chest wall muscles increase pressure in chest/lungs
 - Expulsive phase
 - Airway opens
 - High flow pushed by increased pressure and chest wall muscles shears mucus and debris from the airways

Neurology
Clinical Pathway
Respiratory Care

Impact of Neuromuscular Weakness

- Tremendous redundancy in the lungs
- First signs of borderline respiratory status occur
 - During illnesses
 - Recurrent pneumonias
 - Prolonged frequent colds
 - Difficulty tolerating illnesses
 - While sleeping
 - Persistent nighttime cough
 - Restless sleep, awakenings
 - Morning headache
 - Behavioral changes/fatigue

Neurology
Clinical Pathway
Respiratory Care

Evaluation

- Pulmonary Function Testing
 - Forced exhalation
 - Lung volumes
 - Respiratory Muscle Strength
 - Peak Cough Flow
- Polysomnography (Sleep Study)
- Occasionally bloodwork

Neurology
Clinical Pathway
Respiratory Care

Interventions

- All therapies impact lifestyle
 - Time
 - Effort
 - Expense
 - etc.
- It is a very **personal** decision to determine the best care plan for any **individual**

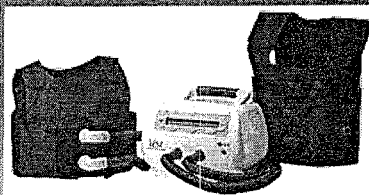
Neurologics Clinical Support
Neurologics
2007-01-01

Interventions

- Immunizations (flu vaccine, AAP schedule)
- Physical Therapy
- Mucus mobilization
 - Manual chest percussion with postural drainage
 - High frequency chest wall oscillators (Vest®)
 - Intrapulmonary percussive ventilation (IPV®)
 - Positive airway pressure (CPAP, BIPAP, ventilator)
 - ❖ Decrease mucus viscosity
 - ❖ DNase (Pulmozyme®)
 - ❖ Hypertonic saline

Neurologics Clinical Support
Neurologics
2007-01-01

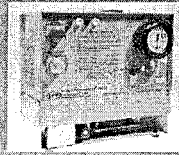
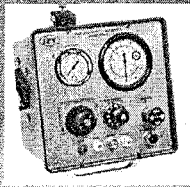
High frequency chest wall oscillators (Vest®)



The
Vest
Airway Clearance System

Neurologics Clinical Support
Neurologics
2007-01-01

Intrapulmonary Percussive Ventilation (IPV®)



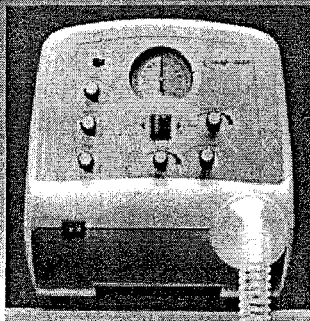
NEPH-4125
Adult - 400-450
Paediatric - 150-300

Interventions

- Sigh and Cough Assistance
 - Inspiratory
 - Simulate sighs and augment cough (inspiratory phase)
 - Breath-stacking
 - One-way valve mask
 - Glossopharyngeal breathing
 - Manual Inflation
 - Expiratory
 - Manually assisted cough
 - Exsufflation (Negative Pressure Assistance)
 - Both
 - Mechanical insufflator-exsufflator (CoughAssist®)

NEPH-4125
Adult - 400-450
Paediatric - 150-300

Mechanical Insufflator-exsufflator (CoughAssist®)



NEPH-4125
Adult - 400-450
Paediatric - 150-300

Interventions

• Respiratory assistance

– CPAP

- Continuous positive airway pressure
- Beneficial when low tone of upper airway causes obstructive sleep apnea
- Increases airway diameter mobilizing secretions

– BLPAP

- Bi-level positive airway pressure
- Rests respiratory muscles
- Improves night time breathing effectiveness
- Increases airway diameter mobilizing secretions

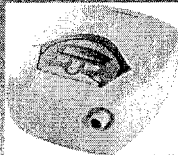
Neurology
Neurology
Neurology

Positive Airway Pressure (CPAP, BLPAP)

Respironics
Synchrony



ResMed
VPAP III

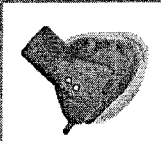


Puritan-Bennet
KnightStar

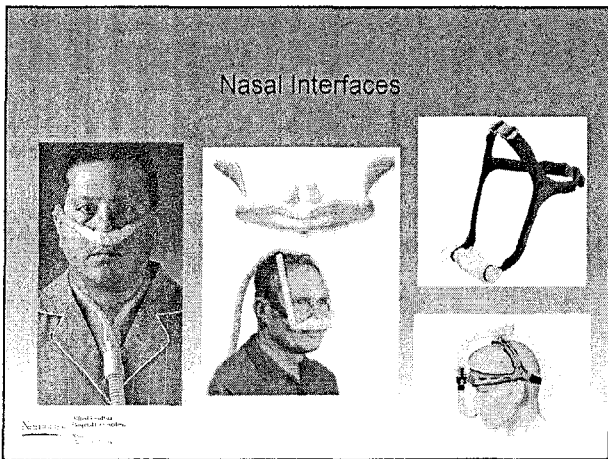


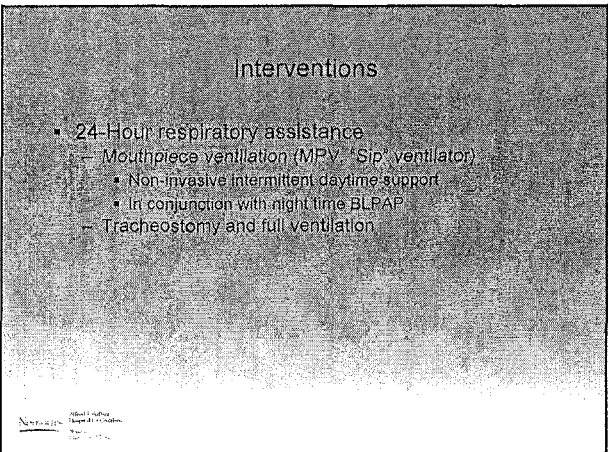
Neurology
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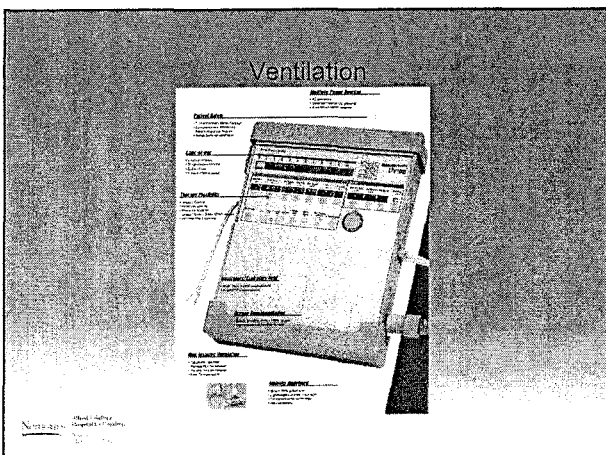
Nasal Interfaces



Neurology
Neurology
Neurology







Finding A Pulmonologist

When should I find a pulmonologist?

- Baseline evaluation (4-6 years of age)
- Using a wheelchair or airway clearance device
- Decreased pulmonary function tests (<80%-predicted)
- Before surgery (weeks to months before)
- Symptoms
 - Recurrent pneumonias
 - Prolonged frequent colds
 - Difficulty tolerating illnesses
 - Persistent nighttime cough
 - Restless sleep, awakenings
 - Morning headache
 - Behavioral changes/fatigue

Which pulmonologist should I see?

- Someone you ***trust***
- Experience caring for patients with neuromuscular diseases
- Resources to support and counsel patients with various levels of respiratory assistance (CPAP, Ventilator, etc.)
- Large Multispecialty Tertiary care facility may be a starting point, but not always the best match
- Internet resources:
 - Muscular Dystrophy Association: www.mda.org
 - ALS Association: www.alsa.org

CATCHING THE WAVE

From High School to College: A Guide to Transition

This publication is designed to help students with disabilities transition from secondary school to college. It will guide students, parents, teachers, and administrators as they begin planning for college. Checklists may be duplicated for student use or for program planning. We hope that students will be "Catching the Wave" from high school to college.

A COMPARISON OF K-12 EDUCATION AND COLLEGE

K-12 IDEA '97	K-12 504 Plan	College 504 & ADA
Success more of a right	No guarantee	No guarantee; student responsible for own success
District identifies disability	Parent provides documentation of disability	Student provides documentation of disability and need for accommodation
Free evaluation of disability	Parent responsibility	Student's responsibility
District develops Individual Education Plan (IEP)	Parent/school develops plan	Student identifies accommodation needs
Entitled to services identified on IEP	Services determined by plan	College services not automatic; each college decides eligibility and services
District ensures that the IEP is implemented	District/parent/student responsible	Student responsible for own progress
Teacher advocate	Parent/student advocate	Student advocates for self
Fundamental alterations to program of study permitted as identified on IEP	Fundamental alterations to program of study permitted as identified on 504 plan	None allowed: Accommodation may not alter fundamental nature of course or impose an undue burden on an institution
Personal services: e.g., transportation, personal attendant, nurse	None provided	None provided

RIGHTS OF ADULTS WITH DISABILITIES

TITLE VI CIVIL RIGHTS ACT OF 1964

Prohibits discrimination based on race, color, or national origin in all employment situations involving programs or activities aided by federal financing.

TITLE VII CIVIL RIGHTS ACT OF 1964

Prohibits job discrimination based on race, color, religion, sex or national origin in all employment practices: hiring, firing, promotions, compensation, and in all other terms, conditions and benefits of employment, including vacations, pensions, and seniority.

SECTION 504 REHABILITATION ACT OF 1973

"No otherwise qualified handicapped individual in the United States shall, solely by reason of his/her handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance...."

AMERICANS WITH DISABILITIES ACT OF 1990

Extends universal civil rights protections to individuals with disabilities, covering public and private sector employment, public accommodations, transportation, and telephone communications.

EDUCATIONAL OPTIONS AFTER HIGH SCHOOL

Programs	Description	Academic Standards	Other Information
Bachelor's Degree (U.C., C.S.U., and private colleges and universities)	Consists of general education courses and courses for the major working toward a four-year Bachelor's Degree. Student may enter from high school or transfer from Community College.	Contact the college to which you are applying. Most colleges have progress policies or grade point average guidelines. If these standards are not met, student may be placed on academic or progress probation. Refer to the college catalog.	Colleges and universities may have different requirements for general admissions. Contact the Admissions Office of the college of your choice for more information. Buy a college catalog.
Associate Degree (Community Colleges)	The Associate degree consists of two components: 1. courses of general education 2. courses toward the major	Contact the college to which you are applying. Most colleges have progress policies or grade point average guidelines. If these standards are not met, student may be placed on academic or progress probation. Refer to the college catalog.	Some community colleges may offer programs to guarantee admissions into a U.C. or C.S.U. See a college counselor for information. Buy a college catalog.
College Certificate (Community Colleges)	College certificate programs are designed to provide employment skills and open vocational opportunities. A college certificate is available upon completion of required courses.	Contact the college to which you are applying. Most colleges have progress policies or grade point average guidelines. If these standards are not met, student may be placed on academic or progress probation. Refer to the college catalog.	These programs change with the current employment market.
Personal Enrichment (Community Colleges)	Community Colleges offer personal enrichment courses that match your personal interests, e.g., career exploration, study skills, computer skills, art, and music.	These classes may be offered on a credit/no credit basis.	These courses may or may not be a part of a certificate and/or associate degree.
Adult Education	Classes are designed to improve basic skills or for personal growth. Examples include adult basic education and English as a Second Language.	These courses usually are not offered for college credit. They may be repeated. These courses are open entry/open exit.	Contact the San Diego County Office of Education for more information.
Regional Occupational Program (ROP)	ROP courses are vocational and designed to prepare for employment.	Students earn an ROP certificate at the completion of course competencies.	ROP programs are offered throughout the San Diego County community. Contact the San Diego County Office of Education for more information.

TRANSITION GOALS CHECKLIST

These are sample IEP or 504 Plan goals for transition from middle school to high school. They are followed by sample goals to help students and parents plan for the transition from high school to college. The time to plan is now! If the following activities are completed during middle school and high school, they will build confidence while preparing the student to enter high school and then college. The activities are organized in a checklist format and can be used in planning transition goals during the IEP process or when writing 504 plans. Use the Glossary at the back to help you understand the

special disability vocabulary you need to learn.

Middle School Transition Goals Checklist

Find Out About Your Disability

- › Name your disability and describe the weaknesses in learning it causes.
- › Identify your strengths in learning; these will help you in school.
- › Identify strategies to compensate for weaknesses and use your strengths in learning.
 1. Learn note-taking strategies for class and identify accommodations, e.g. use of tape recorder or copy of classmate's notes.
 2. Use memory strategies to remember information.
 3. Arrange accommodations for tests, e.g. extra time, and/or a reader.
 4. Pair up with a classmate doing well, to call for questions and study with for tests.
 5. Identify test-taking strategies for multiple choice, short answer, fill-in, and essay tests.

Learn How to Advocate for Yourself

- › Attend all your educational planning meetings, e.g. IEP, 504 Plan.
- › Learn how to ask for accommodations and why it is important to use them now.
- › Ask questions when you don't understand something and get help for all problems.

Develop a Personal Information File

- › Obtain current school records including IEP and latest verification of disability, e.g. Psychoeducational Report, and/or doctor's medical report.
- › Obtain a Social Security Card.
- › Obtain a Birth Certificate.

Investigate Possible Careers

- › Identify possible career interests and education needed.
- › Identify high school classes you need to prepare for your career interests.
- › Identify classes you need now to prepare for high school classes.
- › Identify why current classes are important to meet your career goals.
- › Complete sample college and job applications.

Develop Problem Solving Strategies

Identify possible social problems you may have in school and possible solutions.

Identify possible educational problems in school and possible solutions.

Name people who can help you solve these problems.

High School Transition Goals Checklist

FRESHMAN

Find Out About Your Disability

(Review these each year of high school)

Describe your rights under "Section 504" and the "ADA".

Define "disability" and "functional limitations" according to Section 504 and ADA.

Identify your disability, functional limitations and the accommodations you want to request.

Identify the written verification you will need to request services and accommodations in college. (If you have a learning disability you will need new testing as an adult, 17-18 years old using the WAIS-III or WJ-R Cognitive. You need to request this testing in writing from your high school.)

Learn How To Advocate For Yourself

(By Junior year you should be able to advocate for yourself)

- › Define what it means to "advocate for yourself or to "self-advocate."
- › Identify your academic goals in high school and your plan to meet them.
- › Identify people who can help you solve typical problems you may encounter in school.
- › Define "Due Process" in school/workplace according to Section 504 and the ADA.
- › Attend your educational planning meetings, e.g. IEP, 504 Plan, every year.

SOPHOMORE

Prepare For College

- › Identify 5 colleges you are interested in attending and the majors you may want to study.
- › List the entrance requirements for each college.
- › Identify how your current classes now will help you in college.
- › Contact the disability support office and find out what it offers.

Prepare For College Entrance Examination (4-Year Colleges Only)

- › Identify what test(s) need to be taken.
- › Study for the entrance exam. Enroll in SAT or ACT prep program if possible. Use the study guides.

JUNIOR

Take The College Entrance Examination(s)

- › Pick up test packet(s) from your high school counselor. Apply early and request academic accommodations on application(s) for tests.
- › Begin taking exams as early as possible. This gives you time to retake exams.

Select The College(s) You Are Interested In Attending

- › Plan to visit college(s) if possible. Include disability support office in your

visitation.

- Based on your investigation, pick the college(s) you feel have academic programs that match your interests and will provide you the services you need to be successful.

SENIOR

Select The College(s) to Which You Will Apply (Fall Semester)

- Request an application from the college(s). Fill out the forms and send them in on time.

Apply For Financial Aid

- Pick up a financial aid packet from your high school counselor's office. Complete the application.
- Contact the colleges you're applying to and request any other financial aid applications.
- Request information about other scholarships from your high school counselor.
- Contact local service clubs, state and national disability organizations, and search the local library and Internet for information on scholarships.

You've Been Accepted To College

- Apply with the college disability support office to receive services.
- Provide current written verification of your disability. This must include the name of your disability, functional limitations and academic accommodations you want.
- Make an appointment to meet with a staff member from the disability office.
 1. Identify accommodations you will request and campus procedures to obtain them.
 2. Find out how "Due Process" works on the campus.
- Arrange for other supports not provided by college.
 1. Arrange housing, attendant care, and transportation as appropriate.
 2. Develop a contact list for equipment repairs, interpreters for non-school activities, and medical services, as appropriate.
- Plan classes with a college counselor. Review your selections with the disability support office. Buy a college catalog.
 1. Register as early as possible if you need books on tape or sign language interpreters.
 2. Plan sufficient time between classes to arrive on time and to allow extended time on tests if this is an accommodation you plan to use.
 3. Before classes begin make sure your classrooms are accessible. Problems should be reported to the disability support office.
 4. If you know you need your materials in an alternate format (enlarged print, tape, Braille) request this as soon as possible from the disability support office.
 5. Use breaks between classes to review information from your last class and to preview your notes, syllabus, and homework for your next class.
- Advocate for yourself:
 1. Report problems with accommodations to the disability support office

- immediately. Don't be talked out of an accommodation authorized for you.
2. Learn about all the support services offered on your campus, e.g. tutoring, writing lab, computer lab, and/or counseling center.

Investigate Community Agencies Serving Persons With Disabilities

- Identify community agencies that provide support to persons with disabilities.
- Contact the Department of Rehabilitation to identify what services it offers.
- Identify your local disability advocacy office. Note the services it offers.

VERIFICATION OF DISABILITY

Verification is written proof that a current disability exists. Verification of the disability is the responsibility of each student seeking accommodations and services. The verification must be provided by a licensed professional in the disability related field. Services and accommodations are offered after the formal verification of a current disability.

Application Process to Receive Disability Services

High school students frequently think they are automatically eligible for disability support services at the college level. It is important to understand that this is not true. Under Section 504 of the Federal Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990, you must take the following steps:

1. Complete an application for services.
2. Formally disclose and name your disability.
3. Provide current written verification that:
 - a. names the disability.
 - b. identifies educational limitations that the disability causes.
 - c. identifies reasonable accommodations.
4. Documentation verifying the disability must be recent and from a professional.
 - a. physical, health and psychological disabilities will require documentation from a physician or psychologist.
 - b. learning disabilities and speech and language disabilities require a recent assessment with adult measures.

According to federal laws, you must be able to identify the reasonable accommodations you want to request from the college.

It is recommended that you contact the disability support office at your college for assistance with this process.

STEPS TO SELF-ADVOCACY

Self-advocacy is the ability to identify and explain your needs.

1st step to self-advocacy is to say to yourself, "I am the one who is responsible for my success or failure."

2nd step is to ask yourself, "How does my disability affect me as a student? How do I explain my disability to others? What are my abilities and how can I use them to lead me to success?"

3rd step is to develop good communication skills to request accommodations and services. Successful students plan ahead so they can effectively explain their needs.

4th step is to recognize when you need help and to ask for it.

5th step is to be organized. It relieves stress and demonstrates good planning ability. Here are some helpful hints:

- Use a day planner to record appointments, class schedules, work schedules, exam dates, and assignment due dates.
- Plan a reasonable school, study, social, and work schedule. Allow time for rest and recreation.
- Establish a regular study schedule and study 2-3 hours for each hour you spend in class.
- Organize long-term projects in a step-by-step manner. Schedule deadlines for each step in your day planner.
- Arrive to class on time with homework and assignments completed.
- Discuss and arrange disability services and accommodations you will want at the beginning of each semester with your instructor.
- Allow time for the unexpected such as traffic jams on the way to campus, illness, transportation glitches, or work schedule changes.

Now take some time to think about explaining your disability and accommodations to a professor or your counselor. What would you say? Please fill in the blanks below:

My disability causes the following problems in learning: (e.g., difficulty taking notes, finishing tests on time)

These problems mean I would like: (list the accommodations you will request)

PROTECTING YOUR RIGHTS

Legal Rights For Adults With Disabilities

Protection of rights for people with disabilities began with the Civil Rights Act of 1964. Since then, two important laws, Section 504 of the Rehabilitation Act of 1973, and the Americans with Disabilities Act of 1990, have been enacted. What do these laws provide to you as a college student?

- Both laws prohibit discrimination solely on the basis of a disability.
- Both laws require a college to provide reasonable accommodations so that a student with a disability has equal opportunity to take part in a college's programs, activities, and courses.

Student Responsibilities

As a student with a disability you:

- Must identify your disability and present verification of your disability from a qualified professional to either the disability support office or your professor.
- Must request the accommodations you want from your professor and give reasonable time to arrange them.
- Must comply with the student code of conduct adopted by the college and all other applicable statutes and regulations related to student conduct.
- Must monitor your grades in classes and ask for help at the first sign of a problem.

Institutional Responsibilities:

The college or university:

- Must provide reasonable accommodations based on the problems the disability causes. The institution may not discriminate against you solely on the basis of your disability.

- Does not have to provide the accommodations you request. The institution does have to negotiate reasonable accommodations. The accommodation may not cause an undue financial burden to the institution.
- Does not have to alter admissions or graduation requirements, or change the basic nature of an individual course. This policy is specifically defined in both Section 504 of the Rehabilitation Act of 1973, and the Americans with Disabilities Act.

GLOSSARY

A

Accommodations:

Adjustments made in learning. Alternative ways to access information and show what a student has learned. Accommodations requested must be based on the student's functional limitations.

ADA

Americans with Disabilities Act of 1990: A Civil Rights Law for adults that extends the protections of Section 504 to private schools and businesses.

B

BOGFW

Board of Governor's Fee Waiver for community colleges only. If eligible, some enrollment fees may be waived.

C

College Entrance Examinations:

Examinations taken in the high school years to determine college eligibility.

SAT: Scholastic Aptitude Test

ACT: American College Test

CSU

California State University; public universities in California.

D

Disability

A structural, physical or psychological difference resulting in functional limitations that cause significant problems with learning or work.

Disability Support Office

Offices or departments on each campus providing services and accommodations for students with disabilities. In California many offices go by the following names:

DSPS: Disabled Students' Programs & Services

DSS: Disabled Student Services or Disability Support Services

OSD: Office for Students with Disabilities

DR

Department of Rehabilitation; state agency that provides support to adults with disabilities in seeking education/training toward employment. Adult must apply and meet employment-related eligibility requirements.

Due Process

Legal procedures that determine if a law is being followed. Every college has a procedure for Due Process. When it is believed that a legal right has been denied

to a student, the student has the right to request a review using Due Process.

F

FAFSA

Free Application for Federal Student Aid; this is the required application to receive federal grants, loans, and work-study assistance.

FAPE

Free and Appropriate Public Education; PL 94-142 is the civil rights law passed in 1974 that provides free and appropriate public education for all, including students with disabilities. Applies to K-12 ONLY. (The term K-12 refers to the years in school from kindergarten through the end of high school). This law has been updated and is currently known as IDEA '97.

Financial Aid

Financial assistance to students who might otherwise be unable to continue their education due to financial need.

Functional Limitation

Identified area(s) of weakness caused by a disability. Functional limitations are used to identify reasonable accommodations in school/work.

I

IDEA '97

Individuals with Disabilities Education Act of 1997; federal legislation that states the civil rights of students with disabilities in K-12. Latest version was passed in 1997.

IEP

Individual Educational Plan; IDEA 1997 requires an annual IEP meeting to review and plan goals and objectives (Applies to K-12 ONLY).

K

K-12

The term K-12 refers to the years in school from kindergarten through the end of high school.

L

Learning Disability

A persistent condition of neurological dysfunction. The general characteristics include: Average to above average ability, a significant processing problem, and significant difference between ability and achievement in school.

P

Psycho-Educational Report

Reports of psycho-educational assessment results, including names of ability and achievement tests used, scaled and standard scores earned, and a statement of findings with recommendations.

R

ROP

Regional Occupational Program (see Community Resources).

S

504 Plan

504 plan is used to outline accommodations and services for students with disabilities in K-12.

SEC

Student Education Contract; a required community college plan of study for students with disabilities developed by disability support office and the student.

Section 504

Part of the Federal Rehabilitation Act passed in 1973 to protect the civil rights of children and adults with disabilities in schools or workplaces that receive Federal financial support.

Self-advocacy

The ability to identify and explain your needs. Students with disabilities should understand the laws that protect them and help them achieve their academic goals.

Student Code of Conduct

Defines expected behavior of a college student and consequences. Colleges have both policy and procedures about expected behavior. This information is usually found in the college catalog. Serious misconduct may result in suspension/expulsion. Students with disabilities are held to the same standards as all students.

T

TAG

Transfer Agreement Guarantee; an agreement between the community college student and the receiving four-year school.

Title VI--Civil Rights Act of 1964

Prohibits discrimination based on race, color, or national origin in all employment situations involving programs or activities aided by federal funding.

Title VII--Civil Rights Act Of 1964

Prohibits job discrimination based on race, color, religion, sex or national origin in all employment practices: hiring, firing, promotions, compensation, and in all other terms, conditions and benefits of employment, including vacations, pensions, and seniority.

Transition

Here refers to passage from K-12 to postsecondary education.

U

UC

University of California; public universities in California.

V

Verification

The written proof that a disability exists. It must be signed by a doctor or professional in the field. It names the disability and identifies functional limitations.

The National Information Center for Children and Youth with Disabilities (NICHCY)

www.nichy.org

NICHCY is a national information and referral center that provides information on disabilities and disability-related issues for families, educators, and other professionals. provide NICHCY publications, including fact sheets on specific disabilities, state resource sheets and guides for parents

How about more school? Going on to postsecondary education.

www.ed.gov/about/offices/list/ocr/transition.html

More and more high school students with disabilities are planning to continue their education in postsecondary schools, including vocational and career schools, two- and four- year colleges, and universities. As a student with a disability, you need to be well informed about your rights and responsibilities as well as the responsibilities that postsecondary schools have toward you. This brief tells you what you need to know

The George Washington University HEATH Resource Center

www.heath.gwu.edu

HEATH is a national clearinghouse on postsecondary education for individuals with disabilities. Support from the U.S. Department of Education enables the clearinghouse to serve as an information exchange about educational support services, policies, procedures, adaptations, and opportunities at American campuses, vocational-technical schools, and other postsecondary training entities

National Center on Secondary Education and Transition (NCSET)

<http://www.ncset.org/>

Coordinates national resources, offers technical assistance, and disseminates information related to secondary education and transition for youth with disabilities in order to create opportunities for youth to achieve successful futures.

AHEAD - Association on Higher Education and Disability

<http://www.ahead.org/>

AHEAD was founded to address the need and concern for upgrading the quality of services and support available to persons with disabilities in higher education.

Grossmont College - Disabled Student Programs & Services (DSPS)

http://www.grossmont.edu/dsps/transition/transition00_default.asp

Provides a good range of resources for the process of transition to adulthood in general and to college in particular. Includes the publication, "Catching the Wave: A Guide to Transitioning From High School to College."