Founded in 1989

The Post-Polio Support Group of Orange County Newsletter

15231 Marne Circle
Irvine CA 92604

MARCH 2010

Salk Institute Symposium Part 2

Neuromuscular/Respiratory Effects on Post-Polio Patients & Others

In this issue, we are continuing our series on the findings presented at the Salk Symposium in La Jolla in November, 2009. The first was the basic physiology article on musculoskeletal support for Respiratory Systems and in this article, Dr. Noah Lechtzin, Dirctor of the John Hopkins ALS Clinic, gives us further information on that structure and Diseases affecting it, Diagnostic tools and Treatment. Our final in this series will be run in the May 2010 newsletter on Equipment and Devices for patients who have breathing disorders.

Inside this Issue

BREATHING and SLEEP:

What's the Problem?
What Tests are Needed?

Noah Lechtzin, MD
Pulmonary Director, John Hopkins ALS Clinic

Overview:

Let's talk about Respiratory Problems;
Pulmonary Physiology 101

- Respiratory muscles and mechanisms
- Gas Exchange
- Control of Ventilation

Presentation and Evaluation of Respiratory and Sleep problems

Respiratory Complications in Neuromuscular Disorders are a leading cause of morbidity and mortality. Its complications include:

- Infections: pneumonia
- Atelectasis (collapse of air sacks)
- Respiratory Failure due to:
- Abnormally low oxygen level
- Abnormally high carbon dioxide level
- Sleep Apnea: Obstructive and Central

Fatigue

Causes of Respiratory Complications Primarily due to:

- Weak breathing muscles and the inability to inhale completely
- Inability to cough
- Inability to clear secretions of mucus or phlegm
- Impaired swallowing

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- Increases the risk of:
- Hypoventilation
- Mucus plugging
- Aspiration
- Sleep Apnea

Respiratory System Functions

- Main Function is LUNG GAS EXCHANGE: oxygen in andcarbon dioxide out
- VENTILATION: Movement of air/gas in & out of lungs
- Minor functions:
- Filters Microthrombi (Blood clots)
- Speech
- Metabolism control
- Converts angiotensin I to II
- Inactivates or removes serotonin, bradykinin, norepinephrine, and acetylcholine

Airway Anatomy (*see also January, 2010 Issue for visuals)*

- Upper Airway
- Nasal Cavity
- Pharynx
- Epiglottis
- Larynx
- Lower Airways
- Trachea
- Main Bronchi
- Segmental Bronchi
- Bronchioles
- Terminal Bronchioles
- Respiratory Bronchioles
- Alveolar Ducts and Sacs

These all work in conjunction to conduct the Gas Exchange Process through the Airways and anatomical dead space

Respiratory Muscles

- Inspiratory: Muscles increase thoracic volume, intrapleural andalveolar pressures fall. Air is drawn into the lungs using the Diaphragm, externalintercostals muscles and the Scalene, sternocleidomastoid structures
- Expiratory: Largely Passive Process. Abdominal muscles and internal intercostal muscles are in play

CONTROL OF VENTILATION (Breathing)

- Major Mechanisms are the sensors in the brain that alert the brain to the levels of oxygen and carbon dioxide in the blood.
  - Peripheral chemosensors in carotid body (located in the neck)
  - Sense low oxygen levels
  - Ventilation increases when Oxygen level falls
  - People with chronically elevated carbon dioxide levels may only respond to a FALL in oxygen level
  - People with ELEVATED carbon Dioxide levels may STOPBREATHING when given high levels of oxygen (typical of an EMT response to emergencies)
  - People with Neuromuscular disease SHOULD NOT RECEIVE OXYGEN without ventilatory support and close monitoring

COUGH

- Most people think of this as an annoying problem or symptom. IT ISN'T!!!!!
- It is CRUCIAL for clearing respiratory secretions, avoiding mucus plugging and respiratory infections.
- Effective coughing requires inspiratory, expiratory and bulbar muscle function.
- The Mechanics of Coughing
  - Three Phases
    - Inspiratory
    - Compression
    - Expulsion
  - Job Requirements
    - Intact Nerves & Receptors
    - Functioning Glottis

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- Functioning Inspiratory & Expiratory Muscles
- Adequate Chest Wall Compliance

- Inspiratory Phase
  - Better Elastic Recoil of Lungs
  - Dilates Airways
  - Stretches Abdominal (Expiratory) Muscles
- Compression Phase
  - Glottis is CLOSED
- Expiratory Muscles Contract
  - Intrapleural and Intra-alveolar Pressures rise and can go as high as 300 MM/Hg
  - Expulsive Phase
  - Glottis opens
  - The Expiratory Muscles continue to contract
  - High Expiratory flow rates are generated

SLEEP DISORDERED BREATHING

- Sleep Apnea
  - Intermittent cessation of breathing
    - Obstructive
    - Central
    - Mixed
  - Complications of Sleep Apnea
    - Fatigue and Hypersomnolence
    - Hypertension
    - Possible Diabetes
    - Pulmonary Hypertension
  - Risks for Sleep Apnea
    - Obesity
    - Increasing Age
    - Male Gender Proclivity
    - Neuromuscular Disease
    - Weakness of Pharyngeal muscles
    - Abnormal Respiratory Drive

Neuromuscular Disease and Post Polio (PPS)

- Occurs in Polio Survivors years after recovery from acute infection with the poliomyelitis virus (15-30 yrs later)
- Occurs in 25-50% of polio survivors
- Patients Develop new muscle weakness – often in muscles previously affected but can affect prior uninvolved muscles
  - Fatigue is VERY common
  - Muscle atrophy can occur
  - Muscle and Joint Pain are common
  - Sleep Apnea is common

EVALUATION & TREATMENT

Proper Diagnosis of the Problem is Critical to determine the respiratory impairment. It is Equally Important to Introduce Non invasive Respiratory Protocols Early.

Note: The FAILURE to recognize and Intervene will INCREASE the risk of complications and the need for INVASIVE airway management

- Three Tiered Approach to Respiratory Care
  - Identify, Avoid, Eliminate Problems
  - Ongoing Evaluation of Respiratory Status and treatments
  - Use of Respiratory Aids
  - Ventilatory Support
  - Airway Clearance/Lung Volume recruitment

AN OUNCE OF PREVENTION

- Avoid Infection through:
- Handwashing
- Vaccinations for Influenza and Pneumococcus
- Avoid Sick Contacts
- Nutrition/Choking
- Change consistency of Food and Eating Habits
- Early Use of Feeding tubes is sometimes beneficial

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- Identifying Respiratory Problems
  - Symptoms may be subtle
  - Shortness of breath – especially when lying supine or in water
  - Difficulty Sleeping
  - New headaches
  - Frequent waking
  - Somnolence or fatigue
  - Inability to take Deep breaths or cough
- Symptoms of Respiratory Infection
  - Chest Congestion
  - Fever/Chills
  - Chest Pain – especially with breathing or coughing
  - Persistent Cough or Phlegm
  - Dyspnea, orthopnea, weak cough, increased secretions
  - Dyspnea associated with other medically evaluatedsymptoms

EVALUATION

- Pulmonary Physical Exam
  - Vital Signs – look for Rapid Respiratory Rate
  - General Appearance
  - Working Hard to Breathe
  - Able to speak in complete sentences
  - Use of Accessory Muscles of Respiration
  - Abdominal Paradox – Normally, the abdomen moves out with inspiration
- Pulmonary Function Tests
  - Can Follow Disease Course
  - Diagnose Respiratory Muscle weakness(es)
  - Help Timing of Interventions
  - Ventilatory support
  - Feeding tubes
  - Oxygen (Mostly used in air travel)
- Sleep Testing

Tests are readily available, objective measures of Respiratory function that can be followed serially are essential.

CONCLUSIONS

- Having knowledgeable, accessible respiratory/pulmonaryproviders is crucial
- Wide array of readily available tests can diagnose respiratory muscle problems and direct therapies
- Evaluation leads to multiple life altering therapies
  - Increase cough effectiveness
  - Reverse atelectasis
  - Improve thoracic range of motion
  - Increase Lung compliance
  - Increase speaking volume
  - Non-Invasive Ventilation: Benefits
  - Expand Lungs/Prevent Atelectasis
  - Preserve thoracic Range of Motion
  - Decrease shortness of breath
  - Improve sleep quality
  - Improve "Quality of Life"
  - Improve cognitive function
  - Prolong survival – this provides a greater effect than medications or other treatments

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Watch for next issue (May 2010)
Part III of the Salk Series.
Louis Boitano, U of Washington on **Ventilation Equipment Options.**

POST POLIO, ANESTHESIA AND CATARACTS

by Astrid Gallagher

The time had come for getting my cataracts removed and replaced. All my friends said how quick and easy the surgery had become. So I was a bit surprised when the surgeon told me that all cataracts required anesthesia.

I requested no anesthesia. knowing how dangerous anesthesia can be for a post polio, and remembering my own experiences in the past when I'd been knocked out for hours. I went looking for information. Janet Renizon sent me to the internet, where I found tons of articles. I also contacted Dr. Susan Chun at the Rancho Los Amigos Medical Center.

Armed with this information I again spoke with the surgeon, who basically didn't understand that when lying flat, I can't inhale and exhale for adequate oxygen intake due to muscle power loss in the diaphragm, that has nothing to do with the lungs. I also emailed this information to my own physician, who at age 41 doesn't even remember a polio epidemic. He has one star quality, and that is a willingness to listen. So he went to bat for me, contacting the surgeon, and the anesthesiologist. He suggested to them that if I got oxygen during the surgery I'd do just fine.

Nevertheless, the two surgery centers here in San Luis Obispo both refused to take me, based on their assumption that I had pulmonary issues, and they had no way of monitoring them. In the end the surgery was done at French Hospital, one of the Catholic Healthcare West facilities. According to the surgeon, the instruments they had were outdated, and required him to spend more time on the cataract removal than should have been necessary. Plus, there was only one implant available, with no back up. This implant has caused a high level of inflammation, which if it doesn't improve, the surgery may have to be done again.

The second cataract was replaced at the Surgery Center in Pismo Beach one month later, again without anesthesia, but with oxygen. This time there were no after effects.

If anyone is contemplating a like surgery and has questions about my experience, please feel free to contact me at (805) 549-9283 or on my cell at (805) 234-0523.

Astrid Gallagher
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"Good grief. I think your body rejected your cornea transplant."

Polio Survivors Ask...

Nancy Baldwin Carter, BA, M Ed Psych, Omaha, Nebraska, (n.carter@cox.net)

Q: I attended a support group meeting recently and was very uncomfortable with the denigration of physicians. I know from experience that some health professionals are not familiar with the management of post-polio problems. However, wouldn't we all be better served if groups sought out physicians in the area and worked with them?

A: In a perfect world, we would all have curious doctors who listen to our every word, spend time with us during an office visit, and dedicate themselves to following the examples of post-polio experts. They'd scoff at the idea of pushing pills to mollify their patients or ordering procedures to appease their malpractice attorneys. And they'd always be pleasant.

Also, I'd be able to buy shoes narrow enough to fit my feet—and Coca-Cola would still be selling six-and-a-half ounces of pop in little glass bottles.

Clearly, this is not a perfect world.

While we may not have perfection, however, we do have opportunity. Is there a better setting than a post-polio support group for hatching a plan to recruit doctors and other health professionals to jump onto the post-polio bandwagon?

This, then, begs the question—why would a group choose to spend its time bad-mouthing the very individuals who could be helping them, and in the process create a negative atmosphere bound to ensure that members will leave their meetings grumbling and unhappy?

Perhaps groups don't give themselves enough credit. It may never have occurred to them that they might have the power for change that they actually do have. Think of this:

WHAT IF—
Individual members asked specific doctors for advice on how best to recruit physicians to our cause—and then took this information back to their groups to bring it to life?

Groups invited a small panel of doctors to a meeting to discuss their points of view on ways to interest other physicians in devoting more attention to post-polio problems? What would it take? How would it be helpful to doctors to have post-polio information? Groups would then grab that ball and run with it.

Groups contacted their local medical associations to determine how to place a recruitment article in that association's newsletter—and ask for additional suggestions for accomplishing our enlistment goal?

Groups arranged with local hospitals for a post-polio expert (provided at group expense) to speak at education/training sessions to pique the interest of participants in post-polio issues? (PHI has a list of experts who might help with such a project.)
Sure—there are a million other ways. Start buzzin'. Get some positive energy swirling in meetings, and our fantastic post-polio thinkers will come up with a terrific game plan. Start small. Get detailed. Be fully prepared.

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Next Up: Everybody follows the plan. Let there be no mavericks running around in the hills, going off on tangents that might sink carefully devised projects. Work as a team—where everyone picks roles to play that fit their capabilities and inclinations.

Then, let 'er rip! Everybody involved will gain from the effort. We may not snatch one doctor for the cause, but participating members will be whistling a happy tune come meeting time, nonetheless. And who knows, some far off doc may hear the echo and, well…. There's simply no way cooking up a little pizzazz in a group is a bad thing.

Nancy Baldwin Carter, B.A, M.Ed.Psych, from Omaha, Nebraska, is a polio survivor, a writer, and is founder and former director ofNebraska Polio Survivors Association.

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How to contact Rancho Support Group

The Rancho Los Amigos Post-Polio Newsletter is published as a joint venture with the Polio Survivors Association.

For additional information please call Richard at **562-862-4508**

Or email us:
Rancho PPSG@hotmail.com

How to contact OC Support Group:

Call us for information:
Marte Fuller **562-697-0507**
Marilyn Andrews **714-839-3121**

Newsletter co-editors:
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renison@cox.net

Agenda ideas for PPSG of OC?
Please call Aleta at 949-559-7102 or email Priscilla at prisofoc@aol.com

Special thanks to the following donors: Nancy Norwood, Bonnie Levitan, Cecelia Torres, Elizabeth Adams. and Lois Jackman. We mention donations but not the amount, as all donations make our support group possible. Please write checks to **Polio Survivors Association** and write "Orange County" in the memo section. Please **mail checks to** Priscilla Hiers, Treasurer PPSG of OC, 18552 Cork Street, Fountain Valley, CA, 92708.

Rancho Los Amigos Meeting

Saturday March 27
2 PM - 4 PM
OPEN DISSCUSION
Share **O**ur **S**upport

Future Rancho SG Meetings

Saturday April 24th

Details in April Newsletter

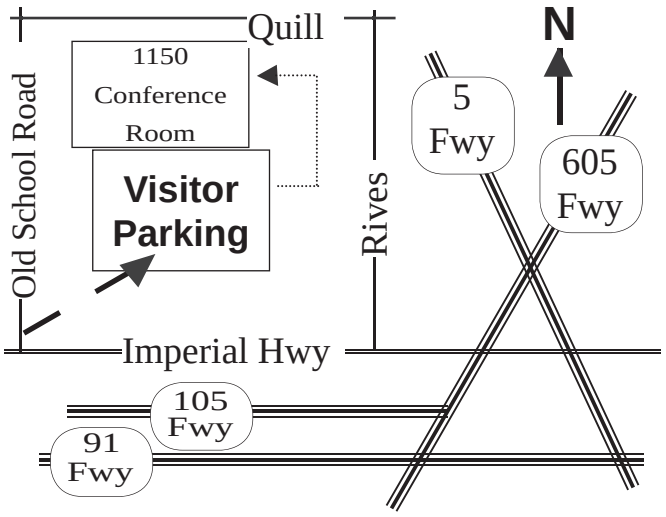
Sunday May 23

Joint meeting with OC Support Group

PPS research and treatments update

Dr. Susan Perlman of UCLA

Villa Park City Council chambers
(see map at right below)



We meet **4th Saturdays 2 - 4 PM**
Rancho Los Amigos
National Rehabilitation Center
7601 E Imperial Hwy Downey
1150 Conference Room
Support Service Annex

Orange County Meeting

Saturday March 14 2PM - 4PM

Post-Polio Medications & Research

- Judy Shigemitsu, a pharmacist who understand post-polio syndrome

VILLA PARK CITY COUNCIL CHAMBERS

See Map Below

Future PPSG of OC Meetings

Saturday April 11-

Eye Disorders in PPS Patients
(Glaucoma, Cataracts, MD, etc.)

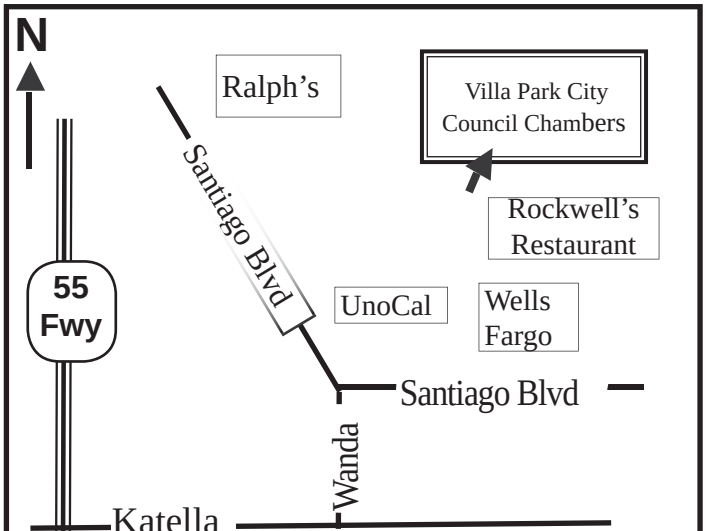
Sunday May 23

PPS research and treatments update

Dr. Susan Perlman of UCLA

Saturday June 12

Getting Seated for a Wheelchair
by St. Jude Medical Center Physical Therapists (TENTATIVE)



We meet **2nd Saturdays** 2 - 4 PM
Villa Park Council Chambers
17855 Santiago Blvd. Villa Park
May meeting usually 3rd SUNDAY
December at Rancho in Downey