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Message from the President

YEAH!!!!

We have a New Secretary: Sheila Kilgore
She is also one of our newest members.
Look for her story in our next news letter.

At our last meeting we had new faces as well as new members. We are growing and I look forward to seeing each and everyone of you. Starting in October we will have moved our meeting place to make it easier for those of you with walkers and wheelchairs.

Also The Court Yard Marriott will no longer be serving lunch for us after our September meeting. So this is why we have moved. Look at our flyer in this newsletter.

Your President, Janice

MOBILITY CHALLENGED? MEET THE SEGWAY

At our next monthly meeting on September 20 at the Courtyard Marriott, Alan Maccini, whose has a spinal cord injury and spent time in a wheelchair, will demonstrate the Segway . The Segway provides another option for mobility, just as a cane, standing frame, walker, or wheel chair does. Alan will tell us about the types of people now using the Segway, a list that includes sufferers of spinal cord injuries, Parkinson's, spina bifida, MS, ALS, Polio, arthritis and amputees.

He will present information about how the Segway has changed many lives. Being able to stand has obvious medical advantages, and even when using the Segway in the seated position it moves the user closer to eye level with others--a huge mental advantage. Alan will also answer any questions we have and will also discuss the "pluses and minuses" of its use, from insurance, the Segway's legal position, and the safety of the machine itself.

Alan Maccini is a member of Disability Rights Advocates For Technology [www.DRAFT.org], a group dedicated to promoting the increase of access to, provision for, and funding for assistive technology devices and assistive technology services. Their goal is to empower individuals with disabilities to achieve greater independence, productivity, integration, and inclusion within the community and the work force.

Don't miss this exciting presentation.



***New Meeting Place
For Our Group***

Beginning with the October meeting we will be holding our monthly meetings at **Piccadilly Cafeteria** **200 Monument Road** **in Jacksonville.**

Be sure to save the insert page in this newsletter for information on meeting dates and other information.



Experts Weigh Giving Up on Killing Polio

By MARIA CHENG
The Associated Press

LONDON -- Nearly 20 years ago, the World Health Organization and its partners launched an ambitious program to eradicate polio by the end of the millennium. That deadline passed and another was missed in 2005, and polio still strikes about 2,000 people a year, mostly children.

At a WHO meeting this week, some leading experts asked a grim question: Is it time to abandon the goal of eradication and focus instead on containing the disease? The answer, for most, was no, even though many had doubts.

"Many people wonder why we are spending all this time and effort on polio when there are much bigger problems," said Dr. Donald A. Henderson, who headed WHO's smallpox eradication program in the 1970s. Smallpox is the only disease ever to have been eradicated.

There is no question the polio eradication program has reaped rewards: Since it began in 1988, the incidence of the disease has dropped by more than 99 percent. But with the number of polio cases at a virtual standstill for the last five years, some experts worry that the campaign by WHO and its partners, the U.S. Centers for Disease Control and Prevention, Rotary International and UNICEF, is running aground.

"Even if things quiet down in the countries where we have problems, there will be another area that bursts into flames," said Dr. Ellie Ehrenfeld, who sits on the WHO Advisory Committee for Polio Eradication.

"We are living in a different world where I'm not sure what eradication means anymore," said Ehrenfeld, who was not invited to Wednesday's meeting.

Critics of the eradication program note smallpox was wiped out in a decade, while the polio campaign is entering its 19th year. WHO is seeking a \$575 million budget for polio eradication for 2007-2008.

In a speech to participants, WHO Director-General Dr. Margaret Chan urged participants not to give up.

"We are facing our best and perhaps our last chance to eradicate polio," she said, adding that leaving the job unfinished would squander the more than \$5 billion invested so far because it would open the way for a resurgence of the disease.

The four polio-endemic countries, Afghanistan, India, Nigeria and Pakistan, are also intent on ridding the world of the virus.

"We will spare no effort in eradicating polio," said Naresh Dayal of India's Ministry of Health and Welfare. This year, India will spend \$286 million to fight the polio virus.

"While eradication is possible, we shouldn't even consider moving to a control strategy," said Dayal.

Others are not convinced.

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A Summer Vacation not for the Disabled



by Janice Askwith

Hi, dear members. This is your president, Janice. I but lately I find that my polio leg gets fatigued in the both crutches. Last year at this time I didn't need two.

usually walk with one crutch, afternoon and I end up using

I had a regrettable vacation in July. I had requested wheelchairs for both my mother and me at every airport. At Jacksonville Airport my 81-year-old mother and I were taken care of right away because we arrived two hours early. The airport at Charlotte, NC was a different story. They didn't have anyone available to push the wheelchairs and asked us to wait. I did not want to miss my connecting flight so I ran with two crutches for approximately two blocks to catch the electric cart. We arrived at our gate only to find out the flight was delayed three hours. We could have taken our time and walked. After arriving at the airport in Dayton, Ohio the results were the same. No one was available to push the wheelchairs, so my mother pushed me to the entrance where my sister waited and took over.

On the way to our family reunion, we ate at several restaurants in small, out-of-the-way towns we passed through on our way from Ohio to Michigan. These places did not have handicapped accessible bathrooms. There was a sign and an overhead hand bar. This is useable only if you could stand up using your right hand above your head to hang on as you forced your way to the toilet seat. If you are in a wheelchair you would have to leave the door open exposing your backside to everyone who entered the restroom, as there is no way to turn around.

Some restaurants will try to make things accessible for the disabled, but sometimes it doesn't matter. My sister from Michigan, who is in a wheelchair, had to go around the back of the building to use the entrance for their supply trucks. The step in front was too high for her to get in. She was embarrassed to say the least.

On the return trip I once again had the opportunity to use both of my crutches. We left the airport in Louisville, KY heading for Charlotte, NC on our way to Jacksonville, FL. We had a delay in Louisville for 40 minutes that almost resulted in missing our flight out of Charlotte. We had an hour and 10 minutes between flights. Normally that would have been enough time. When we landed we were asked to remain seated because our wheelchairs had not yet arrived. We had about 30 minutes to get to our gate three concourses away.

We left the plane and ran to an electric cart, but had to wait for the driver to fill the seats with people. That took about 8 minutes. She then had to fill out paperwork with our names and where everyone was going. I sat in front and told her I would call out the stops for her to save time. Her name was Laura and she said this was the most fun she had all week. I'm just glad I could be there for her. HA!

We arrived at the end of her concourse where there were escalators and elevators. She told us to exit and go down the escalators to the bottom level and wait in the red chairs for the next cart. By this time I had to use the restroom and there wasn't one.. We waited another 5 minutes then we walked in the direction we needed to go, hoping to find a restroom.

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**STATINS:
BENEFITS AND RISKS FOR POLIO SURVIVORS**

Elizabeth Sandel, MD;
Chief of Physical & Rehabilitative Medicine,
Kaiser Permanente Foundation, Vallejo, CA
Presentation to
San Francisco Bay Area Polio Survivors' meeting, April 21, 2007

INTRODUCTION

When I was asked to speak I thought that I should make this relevant to my practice and to your lives. The one thing that kept coming to mind was the issue of statin drugs. They are one of the most commonly prescribed medications and for good reasons. This issue comes up a lot in my practice, not just for people with a history of polio. Other people too also have had symptoms that are suggestive of possible side effects to the medication. So that is why I chose the topic. I hope it will be of interest to you.

I will not ask for a show of hands of number of people who are on statins. I can imagine probably it is in the range of 40 to 60 percent.

Q= What are **nongeneric names for statins**?

A= lovastatin is Mevacor, simvastatin is Zocor, atorvastatin is Lipitor, pravastatin is Pravachol. Vytorin is actually a combination drug. Vytorin is Zetia plus simvastatin (Zocor).

I encourage you to look at your **SFBAPS April 2007 Newsletter**. There is a lot of good information in it. I learned a lot reading it. Of particular interest is the interview with Dr. Golomb, the UC San Diego researcher who continues to do clinical trials studying statins and their side effects.

Another theme that applies here that I want to discuss is that of **benefits vs. risks**. As physicians we are always trying to figure out whether the benefit-risk ratio is high. The other Hippocratic precept involved here is "do no harm". We can't always accurately predict in which people there may be side effects.

In my practice, always flashing on the screen or wall as I see people is "First, do no harm." If there is something else we can do before we give patients medication that will be done. I prescribe medication but I am very conservative in my prescription of medication. Some of you who I have been privileged to treat or care for know that I am really not too willing to stick my neck out and try new things that are not FDA approved. For example, drugs for fatigue and so forth for polio survivors.

So, with all that said and going back and reviewing all this literature, I think certainly there is a major role for statins in the prevention of cardiovascular disease.

SCREENING

These are the cardiovascular artery disease (CAD) screening guidelines:

1. Adults 40-82: screen annually if no risk factors: Total cholesterol, LDL, HDL, Triglycerides (TGs)
2. Adults 18-82 with any non-lipid coronary artery disease factors: tobacco, hypertension (BP>139/89 or on hypertension medication; low HDL (<40); family history of premature CAD; age (men: 45; women: 55)
3. All adults with CAD, diabetes, vascular disease, kidney disease, metabolic syndrome: increased fasting glucose; abdominal obesity; elevated Triglycerides (TGs), elevated Blood Pressure (BP); low HDL (any three); *Coronary Risk Calculator*: BP, ratio of TC to HDL

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I base these guidelines on the Kaiser Permanente cholesterol guidelines which are reviewed every two years. All the clinical practice guidelines Kaiser has are reviewed every two years, and I participate in the stroke guidelines. It is an incredible process. A group of physicians review all the literature for the last two years and update the guidelines. There is a lot of interaction and a lot of discussion and so forth.

When reviewing guidelines on the Kaiser Permanente intranet, I found quite interesting the fact that **Southern CA Kaiser guidelines differ slightly from Northern CA Kaiser guidelines. Lovastatin (Mevacor) is the choice for Northern CA and simvastatin (Zocor) is the top choice in Southern CA.** The reality is that those two drugs are most powerful and in the top three statin drugs. Lipitor is very interesting in that it has gotten more press and marketing. We'll talk a little more about that later.

So, if you are between the ages of 40 and 82 and do not have any risk factors, you still should have an annual cholesterol screening. That screening should consist of a **thorough cholesterol panel -- the LDL (that's the "bad one"), the HDL (that's the "good one"), and the triglycerides (TGs).** Dr. Golomb makes the point, and it's a good one, that it is really not the actual value but the ratio of the total cholesterol to the HDL that is important. If your HDL is pretty high, you are in pretty good shape unless your total cholesterol is high.

Q -- What happens to people who are beyond 82?

A -- That's a very good point. The questions are based on research, and the research is in this population (40-82). There doesn't seem to be necessarily a benefit in the population beyond that. If you make it to the decade of the 80s, probably genetically you have a good predisposition. As the old elderly lose more muscle mass, there may be a higher incidence of side effects. They say that by about age 20 you begin to lose muscle mass.

What are the risk factors for heart disease, or we could say stroke? In general, what we are talking about here is **atherosclerosis**. So it could be arteries anywhere, but the ones where the most research has been done is in the coronary arteries (heart arteries). Scientists don't really understand the process completely. We call it atherosclerosis, but the latest literature suggests that there may be an inflammatory component. That is beyond our discussion here.

Q= How accurate are the blood tests for cholesterol?

A= Pretty accurate.

Kaiser Permanent intranet has on it a **Coronary Risk Calculator**. Kaiser patients can ask their physician to calculate the risk, plugging in certain numbers -- your age, your gender, your cholesterol level and your HDL level, your diastolic BP, and whether you smoke, and whether you have diabetes. It will calculate your ten-year risk of developing or having a MI (myocardial infarction) or heart attack. The calculator is based on a large population-based study, so the risk result is credible.

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You want to try to **control hypertension**. By controlling that you can bring down the cholesterol. The guidelines are pretty much the same everywhere, 139 to 140 for diastolic, and 89 to 90 for systolic blood pressure. What's interesting in the guidelines is there is some benefit if you bring down further to 120 over 80. I almost think there's too much reduction in blood pressure in some older individuals. But the guideline that we use in medicine is basically, if you are not symptomatic, if you are not feeling the effects of low blood pressure, low is probably better. In general you are aiming for at least 139 over 89, and probably lower than that.

NON-PHARMACOLOGICAL TREATMENT

Tobacco cessation

Physical activity (30 minutes per day)

Diet: fats: 25-35% of calories; fiber: 20-30 grams/day; cholesterol: <200 mg/day

Omega-3 fatty acids (from fish: salmon, herring, tuna, sardines, mackerel) or fish oil supplements: 1-3 grams/day; two servings per week

Plant oils: flaxseed, canola, soybean, olive oil; nuts/peanuts/other legumes

Alcohol in moderation; fruits and veggies

Avoid saturated fats: tropical oils; trans-fatty acids, hydrogenated oils: zero!

Weight: as little as 10% reduction; avoid fad diets; BMI: less than 25

Tobacco is a major contributor to coronary artery disease. Certainly, nobody smokes in this group, unless you involuntarily smoke. Maybe I am assuming too much.

So then, how do we advise people? There is a lot we can do in terms of **exercise and nutrition**, so we certainly should try that first.

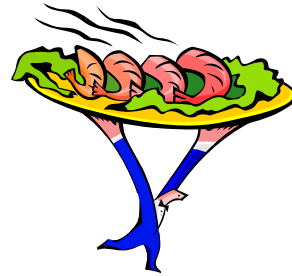
One of my interests in advising people is nutrition, so I want to talk a little about that. It is your health education. I'm not sure the word has been effectively transmitted to people about the risks of some of the food that is on the shelf at the grocery store.

Transfats. There's now a lot of talk about transfat and "no transfat" on labels. How often do you see that on the label? All the time. I've done a lot of research on transfat, otherwise known as **hydrogenated oil**.

Transfats are actually, I think, a **major culprit in the rise in cholesterol level in the world** because now you have mass marketing in processed foods throughout the world. There are some transfats naturally present in certain substances -- dairy products and meat. But in general, it is in processed foods.

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We are MOVING
CHECK OUT THE NEW
SCHEDULE.....

A decorative invitation card with a yellow background and a red border. The card features a central white box containing the text "Your Invited" in a large, black, serif font. Below this, in a smaller black font, is the text "Christmas Lunch: Jacksonville Golf & Country Club December 20th, 2007". The card is decorated with illustrations of pine branches, a lit purple candle in a blue holder, and several colorful Christmas ornaments (blue, yellow, red, and silver).

Your Invited

**Christmas Lunch:
Jacksonville Golf & Country Club
December 20th, 2007**

ATTENTION***ATTENTION*****ATTENTION!!**

NEW MEETING PLACE

Starting with the October 18th, 2007 meeting, our new location for the First Coast Post Polio Support Group meeting and lunch will be:

PICCADILLY RESTAURANT
200 Monument Road
Jacksonville, FL 32225
904-725-5777

DIRECTIONS:

FROM THE SOUTH: Take 9A North and exit on to Monument Road. Turn left at light. Piccadilly is on the right approx 1 mile.

FROM THE NORTH: Take 9A South and exit on to Monument Road. Turn right at light. Piccadilly is on the right approx 1 mile.

We are changing to this location because it offers members more convenient parking and a wider choice of food and prices. This restaurant is a cafeteria that allows you to pick and choose what you like. We will use a meeting room in the back of the restaurant.

PICCADILLY RESTAURANT

DATES: October 18, 2007 November 15, 2007 January 17, 2008

NOTE!!!

September 20, 2007 will be at Courtvard Marriott by the Mayo Clinic off San Pablo Road.

Christmas Lunch Dec 20, 2007:

Jacksonville Golf & Country Club
3985 Hunt Club Road, Jacksonville, FL 32224
off Hodges Blvd

This event must be paid for in advance. The cost is \$18.50 per person. It will be a complete traditional turkey meal with dessert plus entertainment and gifts for all. I must receive your check by December 6th, 2007. Please make checks payable to First Coast Post Polio Support Group. If you have any questions, feel free to contact Janice Askwith, President, at 333-3457 or Sandra Rodrigues, Vice President, at 824-2056.

We look forward to seeing each and every one of you. For those of you who are unable to come, we wish you well. You are always in our thoughts.

Your friends at First Coast Post Polio Support Group

UPDATES WILL BE POSTED TO OUR WEBSITE AT:

www.FirstCoastPostPolio.com

STATINS: BENEFITS AND RISKS FOR POLIO SURVIVORS

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Crisco was the first of the **hydrogenated vegetable oils**, and I believe the **beginning of some of the really serious health problems in our country**. Do you remember your mother always having a can of Crisco in the back of the refrigerator? She used it for baking pies and other foods. The Crisco lasted forever and now we know why. It is the preservative of transfat that allowed it to keep forever.

And then we had the various **margarines** coming out, and so forth. I eat butter but not often. Pure **butter** does not have transfat; just the saturated fat and the caloric content are issues. Again, keep everything in moderation.

What we really have is the presence of transfat in everything imaginable that sits on the grocery shelf. You turn the box over and it says expiration date 2015. How could this be food? You have to religiously read the label.

Even more problematic is that manufacturers can apparently list transfat as "0" if the minimum percentage is below a certain number, I think 1%. So there is still some transfat there. It is not completely about label-reading, but I think it is the best we can do.

Transfat does all the worst things. **The FDA says there is no safe amount.** You'll see the Kaiser Permanente guidelines read something like less than 1% of diet should be transfat. *It should be "zero"!* This is very difficult. This is why I think probably **fresh fruits and vegetables are so important**. It's not so much that they are wonderful, which they are, but if you are not eating processed food and you are eating fresh fruits and vegetables and fresh things you are not getting transfat.

Regarding **meats, they** contain transfat but also have saturated fat.,also not best for you.

Transfats are worse than saturated fats because they prevent the breakdown of cholesterol by the body. You have natural mechanisms in the body that break down cholesterol. They lower HDL and raise the LDL. NY Times recently published an article about the mechanism of how transfat does not allow breakdown of cholesterol. I don't recall what Journal article they were quoting. You have to make a campaign out of completely avoiding transfats.

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Part Two will appear in the next newsletter.

A Summer Vacation not for the Disabled

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As we walked about two blocks three empty electric carts passed by. Each driver asked where we were going and said they would send someone back for us. We were now about 16 minutes before our flight departure and still needed to find a restroom. We waited another 4 minutes and then ran as fast as two crutches would let me. My leg was getting weaker and I didn't think it would hold out before I got to the plane.

Can you picture me with two crutches running down the concourse? Having worn pink that day I looked like a Pink Crane from Florida trying to fly.

What a show!

We came around a corner and there were ten electric carts. Only one had passengers.

I'm tired, hot, weak, fatigued, thirsty and I still need to use a restroom!!

Usually I'm a very calm person. This day was different. I said in a very loud voice, "THIS IS UNCALLED FOR." We received immediate attention.

We were taken approximately four blocks before I got off to use a restroom. Then we walked to our gate and got in line. We would have missed our flight if we had waited instead of walking and running

I didn't have much fun on this trip. We stayed with my sister from Michigan who had just moved into a new home and my niece was sick. We were really glad to get home after two weeks.

Next vacation: Leave early. Don't stay with family. Leave extra time between flights.

I however did see some beautiful clouds. God is still at work.

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A Link to an Interesting and Inspiring Article

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Read the touching story of polio survivor Rex Bernardo of the Philippines whose parents kept his existence a secret and forced him to hide in a cage for 14 years whenever anyone came to their home. He struggled for independence and to achieve his dream of becoming a writer. Here's more proof that PPSers are a strong group of people.

http://archive.inquirer.net/view.php?db=1&story_id=78761

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Experts Weigh Giving Up on Killing Polio

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"We cannot continue forever," said Dr. Isao Arita, another WHO smallpox veteran. "Everyone wishes WHO to accomplish the task but there is a limit."

For WHO, giving up on eradication would be a crushing blow.

"There's an almost religious conviction that they must see this through," said Dr. Samuel Katz, an infectious diseases specialist at Duke University and co-inventor of the measles vaccine.

"But there are other things we could do that would be as beneficial to child health rather than spending another billion dollars in frustration," he said.

In the countries where polio occurs, there are many competing health priorities, including respiratory and diarrheal diseases, malaria and AIDS.

Some experts say that a polio containment policy wouldn't necessarily be radically different from an eradication policy, except that it would free up money for other health problems.

Tighter regulation in countries where polio occurs could help trap the virus, and international officials might adopt measures such as requiring proof of vaccination for travelers coming from polio-endemic countries.

WHO and its partners insist it is possible to eradicate polio, and that the only challenges are logistical.

Different problems plague the four endemic countries: In Nigeria, the weak health system coupled with a vaccine boycott in some areas gets the blame; in Afghanistan and Pakistan, the virus moves back and forth across the border where the official focus is on the war on terror; in India, children are often infected with other viruses, making the polio vaccine less effective.

Some experts think a different vaccine could help. The eradication campaign uses the oral vaccine because it protects entire communities. But while the oral vaccine is cheap and easy to administer, there is a downside: For approximately every 2.5 million doses, it causes one case of polio.

WHO is looking into the more expensive injectable polio vaccine, which uses an inactivated virus that cannot trigger polio. Results from the studies won't be available until next year.

WHO insists it is considering all options, except giving up on eradication.

"Any program would be negligent if it didn't check all the possibilities," said Dr. David Heymann, WHO's top polio official, "but our partners didn't want to hear about a control strategy."

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First Coast Post Polio Support Group
 13119 Blackhawk Trail Ct.
 Jacksonville, FL 32225
 (904) 333-4567

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We would like to thank the
 March of Dimes for their support
 with the mailing of our newsletter.

Next 2 Meetings September 20 October 18

Don't miss our upcoming meetings. But be sure you go to the right location every third Thursday of the month at 12 noon.

September Meeting Only:

Courtyard Marriott across from Mayo Clinic
 San Pablo Road in Jacksonville

New Location Beginning with the October Meeting:

PICCADILLY RESTAURANT
 200 Monument Road
 Jacksonville, FL 32225

As Autumn Arrives

“Autumn is the year’s last,
 loveliest smile.”

William Cullen Bryant

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“Every leaf speaks bliss to me,  
 fluttering from the autumn tree.”

*Emily Bronte*

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“Winter is an etching, spring a
 watercolor, summer an oil painting
 and autumn a mosaic of them
 all.”

Stanley Horowitz

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DISCLAIMER: The articles, opinions, ideas and suggestions presented in this news letter and from our meetings is not to be taken as an endorsement or approval of any medication, product or individual. Always check with your Doctor first about your condition. First Coast Post Polio Support Group of Jacksonville, Florida does not assume any responsibility for individual reader’s action. Information in this newsletter was obtained from various national and local sources which are considered reliable and /or reflect the opinion of the authors. Medical advice must be sought from competent licensed physicians.