

Aug 2006 – Sep 2006  
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Post-Polio Support Group  
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# POLIO EPIC, INC.

**General  
Membership  
Meetings  
Every Second  
Saturday of the  
Month  
10:00 am.  
HealthSouth  
Rehabilitation  
Center  
Wyatt Road**

- August is traditionally our month of “summer vacation”. However, we will still be having our Board Meetings, and our combined efforts of support to one another!

## **Individual Highlights:**

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## The Baton Passes

This two year period, first as President Elect and then as President, has been a busy time for me. In mid-July the project, the long time dream, which I have been shelving, has come to a point which needs more dedication. Some of you know that I have resisted allowing this project to become a preoccupation. In August, as I leave the presidency of Polio Epic I will refocus on this work at providing easier ways to navigate a home specifically designed for mobility impaired persons. For over 50 years I have designed ways to simplify our mobility in new or remodeled homes. The dream is a newly formed corporation called Welcome Home, Inc. With the help of federal and private grant money, I hope to complete a prototype series of homes just for people like us. This is what some of you have encouraged me to do and I am looking forward to this work. Your new President will be Karla Carr, whom I have known for many years to be a dedicated woman of great integrity and gentleness and leadership. We worked well together (sounds like a kindergarten report card, doesn't it?) and I see her talents as a great asset to Polio Epic. Your support during my time as President has been loving and giving and productive. I have been casual about Robert's Rules of Order but with all of the board's help and many of you who are not on the board, we accomplished policies and events and lasting relationships. I certainly encourage some of you who may have considered taking on responsibility with Polio Epic's board of directors, to look deeply at what you can bring to this organization and what this organization can do for you.

I leave this post with much gratitude for your support and friendship.  
Frank Frisina

Hello Polio Epic Members,

Some of you may remember me from the humor workshops I've provided to Polio Epic. Most of you know me for the work done through the federal grant we received for 2005 to develop educational materials on post-polio syndrome for health-care professionals and the general community. ("post-Polio 101") That was an exciting and fun filled year for me. I will be working as your President during September 2006 through August 2007. Since Rotary International has added a goal of "providing support to individuals with Post-Polio Syndrome" to their mission, we have the opportunity to continue providing educational presentations to even more individuals in Pima County and Southern Arizona.

I look forward to the upcoming months and the many opportunities we will have to make a difference in our community. Along the way, let's have as much fun as we can! Blessings  
Karla

*The opinions expressed in this publication are those of the individual writers and do not necessarily constitute an endorsement or approval by POLIO EPIC, INC. If you have personal medical problems, please consult your own physician*

## *New Roles For Growth Factors: Enticing Nerve Cells To Muscles -- 18th July 2006*

- Main Category: Neurology / Neuroscience News
- Article Date: 18 Jun 2006 - 2:00am (PDT)

During embryonic development, nerve cells hesitantly extend tentacle-like protrusions called axons that sniff their way through a labyrinth of attractive and repulsive chemical cues that guide them to their target.

While several recent studies discovered molecules that repel motor neuron axons from incorrect targets in the limb, scientists at the Salk Institute for Biological Studies have identified a molecule, known as FGF, that actively lures growing axons closer to the right destination. Their findings appear in the June issue of *Neuron*.

"The most important aspect of our finding is not necessarily that we finally nailed the growth factor FGF as the molecule that guides a specific subgroup of motor neurons to connect to the muscles that line our spine and neck," says senior author Samuel Pfaff, Ph.D., a professor in the Gene Expression Laboratory, "but that piece by piece, we are uncovering general principles that ensure that the developing nervous system establishes proper neuronal connections."

Understanding how axons find their destinations may help restore movement in people following spinal cord injury, or those with motor neuron diseases such as Lou Gehrig's disease, spinal muscle atrophy, and post-polio syndrome. Failure to establish proper connectivity in the brain may also underlie autism spectrum disorders and mental retardation.

The multitasking members of the FGF growth factor family regulate blood vessel formation, wound repair, lung maturation, and development of skeletal muscle, blood and bone marrow cells. The Salk study adds on more job to an already long list. "Our study emphasizes that the nervous system does not necessarily rely on an entirely new set of molecules to govern axon navigation, but instead uses growth factors already involved in embryonic development in clever and novel ways," Pfaff says.

Skeletal muscle consists of thousands of muscle fibers, each controlled by one motor neuron whose cell body lies in the brain or spinal cord. Connections between muscle and nerve cells are established embryonically when newborn neurons extend axons to "wire" the appropriate muscle fiber.

The wiring process is highly orchestrated - each motor neuron has already pledged allegiance to a particular muscle fiber before it reaches out to connect with its predetermined partner. But until now, scientists could only speculate how the invisible bond was formed.

"The question was how do these motor neurons know where to go," says Pfaff. "It would be a disaster if you wanted to move your arm and instead bent your back."

Earlier studies suggested that muscles lining the spine sent out chemical cues as a siren song for specific motor neurons known as MMCm cells. But when attempts to identify the enticing substance failed, many started to doubt its existence.

After screening numerous candidates, the Pfaff team found not only that FGF is expressed in target muscle, but that FGF "sensors," known as FGF receptors, are expressed in MMCm motor neurons. Furthermore, MMCm axons could not "hear" their muscle partner's call and failed to reach their destination in mouse mutants lacking the sensor molecule.

Finally, using mice engineered to express a fluorescent protein in MMCm neurons, the investigators demonstrated that only the glowing neurons extended axons in the direction of target cells expressing FGF.

"After a lot of hard work, we narrowed it down to FGFs and showed that they were indeed the long sought-after mysterious substance," says Pfaff. Neural stem cells can now be coaxed to develop into motor neurons in a test tube. In that artificial environment, explains Pfaff, "Most external cues that guide immature motor neurons during embryonic development will be missing." Hence the need to identify axon guidance factors.

Continued from page -2-

He continues, "It is not enough to make the right cell type, you need to connect them to the right target. Growth factors like FGF may be crucial to persuade and guide them towards the desired destination."

Additional contributors to this study included first author Ryuichi Shirasaki, Ph.D., a former postdoctoral fellow in Pfaff's lab and now a faculty member at Osaka University, Japan; postdoctoral fellow Joseph W. Lewcock, Ph.D.; and research assistant Karen Lettieri, both at Salk.

The Salk Institute for Biological Studies in La Jolla, California is an independent nonprofit organization dedicated to fundamental discoveries in the life sciences, the improvement of human health, and the training of future generations of researchers. Jonas Salk, M.D., whose polio vaccine all but eradicated the crippling disease poliomyelitis in 1955, opened the Institute in 1965 with a gift of land from the City of San Diego and the financial support of the March of Dimes.

Contact: Gina Kirchweger  
Salk Institute

We want to welcome a NEW member to Polio Epic –

Kathy Zettlosen,

who is not only a polio survivor herself, but also a health professional counselor. What a great addition to our well-educated and caring group!



"We're trying a more holistic approach to our surgeries."  
Total cases of poliovirus worldwide: 699  
Polio cases in 2006 as of week of 11 July 2006

Nigeria (endemic)	529
India (endemic)	81
Somalia (importation)	25
Afghanistan (endemic)	16
Namibia (importation)	13
Pakistan (endemic)	11
Bangladesh (importation)	7
Ethiopia (importation)	6
Niger (importation)	4
Democratic Republic of Congo (importation)	3
Indonesia (importation)	2
Yemen (importation)	1
Nepal (importation)	1

*Our Condolences and prayers go to the family and polio epic members in the passing of Dr. Richard Killebrew. He will be fondly remembered for his generosity (to Polio Epic in particular) and the love of his family.*

*Bert Petri  
He will be remembered fondly by his family and all of us at Polio Epic.*

*Please remember our "lost" members and families in your thoughts of comfort and care*



Just a quick note to tell you that We already have a date set for our Holiday Party at the Holiday Inn Palo Verde. Set your calendars now for Saturday December 9<sup>th</sup>. It was a GREAT event last year, let's see everyone there again this year!



We wish to express our appreciation for March of Dimes, in helping us fund this newsletter. They have given us a grant in order to keep up the communication via this newsletter. Also, please note that the March of Dimes is one of the Sponsors of the work done at the Salk Center as reported in the Article "New Roles for growth factors". Our appreciation goes out to this organization and the work they do.

### Surgery Gets Stroke Patients Moving June 23, 2006

Physical therapy doesn't always help stroke survivors get their arm and leg movements back. Some patients must either live with their disabilities - or opt for a surgery being done at the Hospital of the University of Pennsylvania that brings brain and body in harmony. The surgery is called neuro-orthopedics... And many of the techniques were pioneered by a doctor at the University of Pennsylvania. Sometimes, muscles or tendons are lengthened, or their positions in the body are changed. 3 years ago, without warning, Liz Lewis suffered a stroke. The 45-year-old mother of three couldn't take care of herself or her family for more than a year.

**Liz Lewis**, Toms River, New Jersey: I couldn't see, I couldn't speak. I couldn't move my right arm, and everything in here, my leg and foot were paralyzed. Her sight and speech came back in a few months, and rehabilitation got her walking again. But she could only go short distances in a heavy brace.

**Liz Lewis**. I wanted to die, I say that, ok. I didn't really want to, but I couldn't get any further than I was.

Then she found Doctor Mary Ann Keenan at the

University of Pennsylvania. Her specialty... surgery that gives brain-injured patients more freedom to move. Dr. Mary Ann Keenan/Hospital of Univ. of Pa. Since we can't fix the brain, what we do is you try to fix the consequences of the brain injury in the arm or the leg. So we move the muscles and tendons around. Dr. Keenan analyzed Liz's movement patterns.

Since the brain sets a new pattern for moving muscles after a stroke, this surgery helps the body and brain work better together. For example, to correct an inward twisted foot, the surgeon splits a tendon and re-attaches it in a V, to pull the foot equally on both sides.

**Dr. Keenan**. You're taking a mechanical solution to a much more complicated neurologic problem. 3 surgeries later, Liz walks without thinking about it.

**Liz Lewis**. It's a whole year. One, two, three and I am like a different person.

The surgery may also help patients with spinal cord injuries, cerebral palsy, multiple sclerosis, and **post-polio syndrome**. About 70 per cent of eligible patients are able to walk again without a brace.

#### Donors and Contributors:

Arlene Friedman  
Charles Immler  
Debbie Munhall  
Frann Miescher  
Katherine Zittlosen  
Linda Gallagher  
Loland Cummings  
Mary Kopke

Your Donations in Time,  
Money or Talents are all  
appreciated and Polio Epic  
thanks you for helping and the  
valuable work we ALL do.



#### Thanking BASHAS

#### And all the Polio Epic Members who shop at BASHAS.

Bashas has had a long term program that helped with contributions to various charities and fundraisers. We received a check in the amount of \$58.64. This money came from percentages of the grocery receipts that the shoppers indicated Polio Epic as the recipient. Thank you!

## Polio-hit, she toppled a dynasty

Clement Mesenas - Editor-at-Large - clement@newstoday.com.sg

It wouldn't be an exaggeration to say that Grace Padaca's is the face of hope in Philippine politics. Two years back, Ms Padaca was elected governor of Isabela province in the northern Philippines and wrested power from the Dy dynasty that ruled her home province for four decades. And she just happens to be polio-afflicted.

Her victory was a talking point at an Institute of Southeast Asian Studies forum last week, where academics trotted out their theories on what President Gloria Arroyo had to do for the country. But Ms Padaca, 42, who walks with crutches, told the forum: "I fend for myself and I am teaching my people to be independent, not to be beholden to Malacanang (the President's palace)."

A crusading radio commentator before her entry into politics, Ms Padaca, who was afflicted by polio at the age of three, has wasted no time in putting in place reforms in her home province.

"For a start, I broke the monopoly of the middle man in my province, the people who control the prices of farm produce, buying cheap and selling at much higher prices in the market," she told Today. To do that, she invited agents from outside of her province, a move which enraged the entrenched operators. The competition resulted in higher prices for the farmers. And at the height of the season, when prices fall, she uses public funds to buy up surplus produce and store it.

At the end of the season when prices go up, she puts the produce in the market. From the profits, she is able to make small loans to the perennially out-of-pocket farmers to tide them over till the next harvest. "We should free ourselves from the strictures of the old ways – imposed by wealthy landlords and a President who only visits us after a typhoon has wrecked the province," she said.

Ms Padaca has also cracked down on timber poachers. Despite her physical disabilities, she works 15-hour days, starting with an hour of prayer at 6am. "I sleep from 6 in the evening till 10 pm, wake up to do my paperwork till 2 am, and then go back to bed again," she said of her

working style. She is a much-sought-after inspirational speaker, both as a giant-slaying politician and a champion of the physically challenged.

Ms Padaca had been a multi-awarded radio commentator for 14 years championing the causes of the poor before she decided to take on the Dy family. A daughter of school teachers, she chose a radio career because she could reach the public while keeping her disability out of sight. But her wish to remain invisible was outweighed by her sense of outrage at the Dys' monopoly on power. But she had no illusions about winning – she had no money, no party, no political base. The Dys did not take her seriously. Her campaign vehicle was a farm truck, which she borrowed to cover 278 villages. She had 8 to 10 young volunteers. Her campaign funds came from small donations of 50 to 100 pesos (\$1.50 to \$3), reaching a total of 800,000 pesos (\$30,000) – a minuscule sum to mount a campaign for governorship. But her message on radio – three 15-second slots daily – must have struck a chord (Isabela for all, not for a few) and her riding around in an old truck, stopping in a village, and conversing with the people, must have been very effective, because at counting time, the shock came: She won 55 per cent of the vote.

Fearing that the Dys would tamper with the ballot boxes, her supporters, 3,000 of them members of an evangelical church, stood on guard. Today, Ms Padaca occupies a five-room bungalow on top of a hill, the official residence of the governor. But she never expected that the mansion would become her home. The last governor, Mr Faustino Dy Jr., the third successive member of the Dy family to run the province, had erected the white, Mediterranean-style villa shortly before the last election. "He thought he was building it for himself," Ms Padaca said with a grin, "but actually, he was building it for me."

A slight woman with intense brown eyes, she admitted that winning was easier than governing. Her passion shines through. "I tell people, 'Don't take pity on me. I can take care of myself. Take pity on yourselves. You are still poor after 40 years under a dynasty.

**"You don't have to be imprisoned all your lives'."**

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## Dues Form

**POLIO EPIC, INC. CURRENT MEMBERSHIP ANNUAL DUES ARE RENEWABLE THROUGH THE FISCAL YEAR OF SEPTEMBER 1, 2005– AUGUST 31, 2006**

Name \_\_\_\_\_ Spouse \_\_\_\_\_ Date \_\_\_\_\_

Address \_\_\_\_\_ Phone (\_\_\_\_) \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_ - \_\_\_\_\_

**Emergency Contact info:** \_\_\_\_\_

≡ Email \_\_\_\_\_

\_\_\_\_\_ I am sending in my/our annual dues of \$5.00 per person for 2005-2006 fiscal year.

\_\_\_\_\_ I am sending in a *tax-deductible* donation in the amount of \$\_\_\_\_\_.

**POLIO EPIC, INC.** is a 501(c)(3) non-profit corporation. Tax ID # 74-2477371

\_\_\_\_\_ I am UNABLE TO PAY dues at this time, but wish to continue my membership and receive the newsletter.

\_\_\_\_\_ Please remove my name from the mailing list. I no longer wish to receive the newsletter.

\_\_\_\_\_ Check here if you do not want your name, address, phone number and email listed in the **POLIO EPIC DIRECTORY**.

\_\_\_\_\_ I would like to be more involved in Polio Epic. Please contact me at the number above.

Make checks payable to POLIO EPIC and return this form to Polio Epic, P.O. Box 17556, Tucson, AZ 85731-7556

## Board of Directors

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## **MARK YOUR CALENDAR**

**General Meetings:**

August - Vacation

Sept. 9<sup>th</sup> –10:00 A.M.

**Board Meetings:**

*First Thursday of each month at*

*DIRECT on Tyndall*

**ALL ARE WELCOME!**

## *Executive Board Officers 2005-2006*

<b>President, Karla Carr</b>	318-1219	<a href="mailto:KarlaKrazies@peoplepc.com">KarlaKrazies@peoplepc.com</a>
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