



# NEWSLETTER

ADVOCATES FOR PEOPLE WITH  
DEVELOPMENTAL DISABILITIES

SEPTEMBER 2016

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P.O. Box 1692

(914) 493-1318

White Plains, NY 10602

## LOOKING AHEAD

**Many changes  
are on the horizon...**

Join **Paul Francis**, Deputy Secretary of the  
Department of Health and Human Services  
to discuss:

- **Managed care**
  - Will services be cut?
  - Who will advocate for you?
- **Self-Determination**
  - Constantly evolving rules
  - Can SD coexist with managed care?
- **Residential options**
  - What exactly are the choices?
- **Keeping qualified staff employed in this field:**
  - Need for cost of living (COLA) increases
  - Financial support for mandatory minimum wage
- **Family/Guardian Bill of Rights**
- **NY State Budget**

**Bring your thoughts and questions!**

**Come to the  
GROW General Meeting**

**Sunday, October 16, 2016**

Brunch & Networking: 10:30 a.m. Meeting 11:00 a.m.

At WIHD – Cedarwood Hall

Westchester Medical Center, Valhalla, NY

*Parking vouchers available*

*(Directions on page 3 of this newsletter)*

## PRESIDENT'S MESSAGE...

The return of Fall brings with it our annual general membership meeting, this year on Sunday, October 16th, 2016. The 11:00 AM meeting will be preceded by a light buffet breakfast at 10:30 in the lobby at Cedarwood Hall. We invite all family members to join us along with many of our elected representatives as we welcome Mr. Paul Francis, Deputy Secretary of Health for New York State who will address our assembly.

The 2015-2016 year has been a unique experience for GROW. Several new members have been elected to the Board and are beginning to be comfortable in their designated roles. I have the good fortune to be able to draw on Barbara Masur's eight years as President as we continue to grapple with many of the same issues that have confronted our community for many years. The most daunting is the need for residential opportunities for our now adult family members with developmental disabilities. As OPWDD with Acting Commissioner Delaney undergoes the changes that have been outlined by the Transformation Panel, the future appears to be shaped by two very compelling forces traveling in quite opposite directions. As the number of people with developmental disabilities continues to grow, the federal and state positions seem to be away from out-of-home residences towards keeping individuals in their family home with supports. In the end, this approach is offered regardless of need or benefit because it always is the cheapest. Alternatively, the Self-Direction model is proposed as a vehicle to develop smaller residences, yet families

*(continued on page 2)*

*(President's Message continued from page 1)*

as well as providers are frustrated by the constantly evolving rules. We are also troubled by funding that is insufficient to meet safety needs. Perhaps the biggest issue is understanding and navigating a system with so many moving parts that even the lexicon is a mystery to many.

Please join us at our monthly Board meetings to see how you can help to improve the future of our family members. As we've all learned, the work must continue to match the task. We need to understand, decide and act to provide the most appropriate, safe future for our loved ones; they deserve nothing less.

**William E. Mayerik**  
**GROW President**

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## **GROW LEGISLATION REPORT**

In the fall of 2015 GROW Board Members Will Mayerik, Barbara Masur, Dan Maillet, Stacy Osborne, and Mary Dantin met with Paul Francis, then the newly appointed Deputy Secretary for Health and Human Services. GROW was the FIRST group representing people with developmental and intellectual disabilities to meet with Deputy Secretary Francis. Mr. Francis asked questions, listened to our concerns and took many notes.

**TRANSFORMATION REPORT:** GROW gave input to and responded to the Transformation Report. As far as residential development, we feel that very little has changed. We continue to request clarification of new regulations.

**SELF-DIRECTION:** Mary Dantin continues to keep abreast of ongoing changes in self-direction, and how changes affect persons requiring services on a 24/7 basis. At long last we received a statewide breakdown of the number of individuals in residential development utilizing self-direction.

**FUNDING:** A small group at GROW is investigating the effects of rate rationalization on services.

**GUARDIANSHIP:** Efforts to change guardianship have currently been stalled. Stacy Osborne continues to monitor the situation.

**FAMILY BILL OF RIGHTS:** Even though it was passed in the Assembly, the bill went nowhere in the Senate. Also, as written it did not have the support of OPWDD. We will try and get guarantees from OPWDD that if it is reworked they will come on board.

**SPRING 2016 MEETING IN ALBANY:** Our meeting with our legislators arranged by Assemblyman Pretlow was attended by nearly all our legislators in person, and those who didn't attend sent representatives. Our meeting with Acting OPWDD Commissioner Delaney and Deputy Secretary Francis afforded us the opportunity to once again express our views.



*GROW President Will Mayerik and Past President Barbara Masur and other SWAN members with Acting Commissioner Kerry Delaney*

**SWAN (State-Wide Advocacy Network):** We continue our relationship with SWAN. We have monthly telephone conversations and many e-mails keeping us abreast of developments. There was a SWAN meeting with Paul Francis held two weeks before the March Albany GROW meeting. In addition, SWAN had a meeting in June with Acting Commissioner Delaney, Helene DeSanto and Greg Roberts. We plan to meet with them and Deputy Francis again in late October in Albany.

We have been apprised of several lawsuits, one involving lack of residential development, the other involving day services. We plan to keep track of these lawsuits.

As you can see, GROW is involved in many areas. If there are issues that concern you, come to a Board meeting or communicate them to GROW. Also join us in the ongoing quest for services for all persons with intellectual and developmental disabilities.

**Barbara Masur,**  
**Legislation Chairperson, GROW**

## DID YOU KNOW...

GROW is a founding member of The State-Wide Family Advocacy Network of New York State (SWAN of NYS). SWAN is dedicated to advocating for individuals with Intellectual and Developmental Disabilities. It is an independent coalition of families and guardians of people with Intellectual and Developmental Disabilities. Caring for loved ones is its members' life-long commitment.

Other founding members include:

### **DDAWNY Family Committee**

in Western New York

Contact: Barb DeLong (716) 877-7007

[www.ddawnyfamilycommittee.org](http://www.ddawnyfamilycommittee.org)

[ddawnyfamilycommittee@gmail.com](mailto:ddawnyfamilycommittee@gmail.com)

### **ENYDDA in Albany Region**

Contact: Patrick Curran (518) 774-0492

[ENYDDA@gmail.com](mailto:ENYDDA@gmail.com)

### **NYC FAIR in New York City**

Contact: Elly Rufer (917) 833-4738

[www.nycfair.org](http://www.nycfair.org)

[nycfair@gmail.com](mailto:nycfair@gmail.com)

The SWAN website is <http://swannys.org>.



*GROW President Will Mayerik and Board members Mary Zingaro and Marilyn Vitale with Dr. Susan Fox, the new CEO of WIHD.*

**We're Here for YOU.**

**You can get us through e-mail**

**[Info@grow-ny.org](mailto:Info@grow-ny.org)**

**Find out about us through the web**

**[www.grow-ny.org](http://www.grow-ny.org)**

**and there is always the phone**

**(914) 493-1318**

## Directions to Cedarwood Hall - WIHD WESTCHESTER INSTITUTE FOR HUMAN DEVELOPMENT

**FROM THE SOUTH:** Sprain Parkway North to Eastview - 100C - Exit. Go Left.

**\*\* At Hospital entrance (Second light) go right. Go 4/10 of a mile (passing the county jail) and go left following the sign for All Other Facilities. When you get to the T intersection bear right until the Stop sign. Turn left around oval.**

**FROM THE NORTH:** Sprain Parkway South to Eastview 100C exit. Go right. Follow directions from \*\* above.

**FOR PARKING:** Go around circle, pass through parking ticket dispenser and park in lot opposite Cedarwood Hall. Ask for parking voucher at reception desk.

**BUS DIRECTIONS:** Routes 1, 15, and 14 will leave you off at Elmwood Hall, a short distance from Cedarwood Hall. Route 40 will leave you off at Westchester Hospital, a longer walk.

As a GROW member you receive minutes of Board meetings as well as the agenda of upcoming Board meetings. In addition, news, programs, hearings, etc. are sent to you. Many of you have not given us your e-mail. If you want to be kept up-to-date, please e-mail us at [info@grow-ny.org](mailto:info@grow-ny.org) along with your phone number and address.  
***Edie Shumansky, Membership Chairperson.***

You can send a contribution to GROW in memory or in honor of an individual. Printed acknowledgements will be sent to the proper individuals. You will also receive an acknowledgement. All contributions are tax deductible. Checks should be made out to GROW with all the pertinent information and sent to GROW P.O. Box 1692, White Plains, NY 10602.

***Cynthia Ferguson, Treasurer***

***GROW State of Officers  
and Board Members for 2016-2017:***

**OFFICERS:**

President.....William Mayerik  
 1st Vice President.....Daniel Maillet  
 2nd Vice President .....Stacy Osborne  
 Recording Secretary.....Ray Garofano  
 Corresponding Secretary.....Rochelle Kessler  
 Membership Secretary .....Edie Shumansky  
 Treasurer .....Cynthia Ferguson

**BOARD OF DIRECTORS**

**2017**

Lirio Covey\*  
 Sheryl Frishman  
 Mary Green  
 Leonard Spano  
 Anne Steinberg  
 Marilyn Vitale

**2018**

Mary Dantin  
 Sharon Gelfand  
 Marilyn Hahn  
 Maryann O'Toole  
 Nortrud Wolf Spero  
 Alice Stratigos

**2019**

Judy Frank  
 Shelley Kessler  
 Sharon McDowell  
 Rita Ross  
 Phyllis Smith  
 Mary Zingaro

**Past Presidents:**

Nat Mills (deceased), Morton Steinberg (deceased),  
 Kenneth Plath, Diane Greble; Jackie Fowler; Janet  
 Sugar, Barbara Masur

**\*New Member:**

**Lirio Covey** a resident of Yonkers, is the mother of 37-year-old Michael Lee Covey who lives in a WARC group home in Armonk. Michael attends the day habilitation program at Young Adult Institute in Tarrytown. Lirio is married to Michael H. Covey, a retired computer and systems specialist, and has an older son, Billy, who lives with his wife and children in Manila, Philippines. Lirio founded the Association for Adults with Autism Philippines, Inc. (AAAP). Since 2012 she has organized annual educational symposia in Manila that focus on raising awareness and knowledge regarding issues affecting the lives of adults with autism. A second major project of AAAP is to develop an autism residential program in the Philippines. Lirio has been on the faculty of the Department of Psychiatry at Columbia University and the New York State Psychiatric Institute, holding the position of Professor of Clinical Psychology in Psychiatry. Her expertise area is nicotine dependence comorbid with psychiatric conditions including depression, anxiety, substance abuse, and attention deficit hyperactivity disorder.

***Rochelle Kessler, Chairman, Nominating Committee***

**GROW MEMBERSHIP APPLICATION or RENEWAL**

*(please print)*

Name \_\_\_\_\_

Address \_\_\_\_\_ City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

Phone \_\_\_\_\_ Email \_\_\_\_\_

Membership Application  Renewal

Family (\$20) \_\_\_\_\_ Single Parent/Guardian (\$15) \_\_\_\_\_

Contribution beyond dues \_\_\_\_\_

GROW, Box 1692, White Plains, N.Y. 10602  
 GROW is a not-for-profit, tax exempt organization

To check your membership status, look at the mailing label. If there is a "17" next to your name, you are up to date with your membership, and need not renew. Please accept our apologies for any inaccuracies, and please inform us of them.