



# Guardian

Spring 2002  
Volume 54 No. 2

A publication of The ARC of Essex County, a non-profit agency serving persons with mental retardation and their families since 1948.

## **Respite Help For Autistic Families May Be Endangered!**

I recently gave a speech to the Legislature on behalf of the families of children with autism. The goal of my testimony was to get continued funding for much needed respite help.

As a parent of twins with autism, I believe that the most effective way for me to let the Legislature and general public know how life is for families with autistic children would be to briefly share my personal story.



Six weeks before I gave birth to twin boys, my precious stepson committed suicide. Sixteen months later, my twins - Matthew and Michael- were both diagnosed with serious developmental delays, speech disorders and autism. My husband and I were grieving, depressed and overwhelmed. Soon after that I discovered I had been running after my boys for over a year while I had two fractured feet. It became unbearably painful and difficult, so I finally got medical help.

My autistic sons have what is called "escape behaviors." This means their caregiver must know how to watch them literally every second. The boys may bolt out a door and into traffic with no sense of fear and no intention of stopping. So, I must be on constant guard against danger for them. We have no family living near us that wanted to get involved, so we have no one to help us.

It is very difficult to find someone capable of taking care of all of the twins' special needs. They

each have several challenges. The behaviors that go along with autism can be extremely odd and cause us to isolate ourselves because of them. Some of us have children that are too strong for us to restrain. Autism is a disorder that frequently affects a person's behavior, communication, and social abilities. It can be from mild to severe; therefore it is possible for someone unfamiliar with autism to fail to recognize it.

Going to the grocery store can bring on impatient and judgmental looks from strangers. Autistic kids have an extraordinarily difficult time with waiting, and they have horrible reactions and may appear



[Continued on page 3]

## A Stepping Stones Success Story "The Sensory Diet"

Some of our Stepping Stones students have difficulties with sensory integration. Often, it prevents them from participating in activities, attending to lessons or tolerating environmental stimuli. These children can be greatly helped by an individualized "sensory diet," designed by the staff working with the student's family. The diet is made up of sensory routines that may include therapeutic swinging, bouncing, rhythmic walking, oral motor exercises and therapeutic listening exercises. Once a "sensory diet" is developed, the routines are incorporated into the child's day at school and at home.

Since 1999, Stepping Stones has had a sensory integration program that has brought about dramatic, positive changes in many children.

The children with "sensory diets" pay attention to their lessons, have strategies for coping with their environments and show great improvement in relating to the world around them. We applaud the therapists and teachers whose expertise is vital in implementing these valuable interventions:

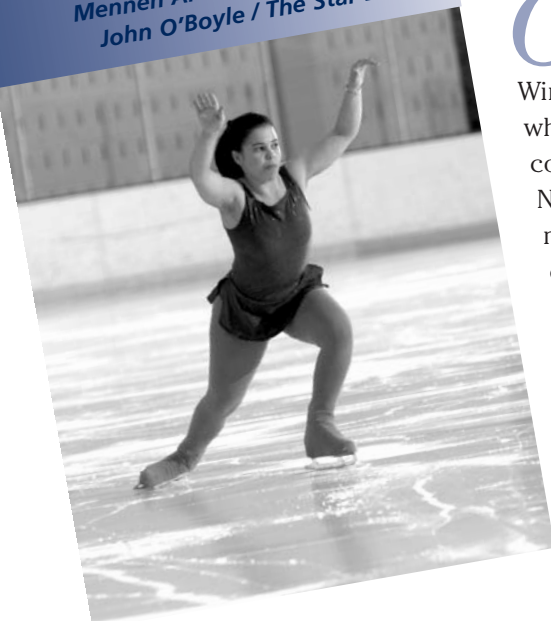
- Ruth Skudera and Patricia Van Houton, licensed physical therapists who have been with the school for over 20 years
- Barbara Ashurst and Ellen Narucki, certified Special Education teachers who have been at Stepping Stones for over 10 years
- Shabana Kahn and Barbara Dashfield, our newest certified Special Education teachers who joined Stepping Stones last year.

Speech therapists and occupational therapists round out the "sensory diet" team.

Special needs receive special care Shabana Kahn works with Shama Leuva.



Nadia shows her form at the figure skating competition at Mennen Arena in Morris County. John O'Boyle / The Star Ledger



## Special Olympics Skill, Courage, Sharing, Joy

Our very own Nadiuska Negron was among the 629 athletes who competed in the four-day Winter Games of the New Jersey Special Olympics, where she took part in the figure skating competition. A new member of the SWOP program, Nadia is always willing to help others and has made many friends there. She works very hard at cleaning and landscaping. Recently, she volunteered to help a consumer who was new to the program and had limited knowledge of English. With her fluent Spanish, Nadiuska made the transition smoother for this other newcomer. Nadiuska, The ARC is very proud of all of your achievements.

## TIPS FOR PARENTS ON GUARDIANSHIP

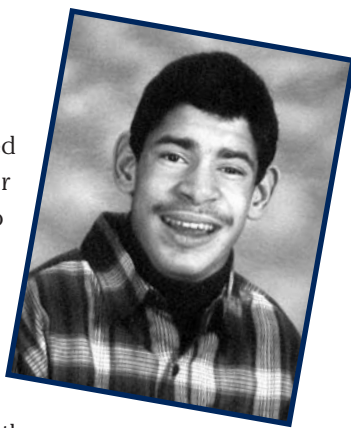
Parents seeking guardianship of persons receiving services from the Division of Developmental Disabilities now can use a packet of forms and instruction provided by the Judiciary. The packet is designed for litigants that want to represent themselves in court to obtain guardianship of an incapacitated person who is older than 18 and receiving services from DDD. In such cases, a parent or other relative typically seeks authority to make decisions concerning the living arrangements, finances and estate of an adult who is unable to manage his or her own affairs because of developmental disabilities.

For a caregiver to obtain guardianship, the person with developmental disabilities must be considered incapacitated by both the DDD and an independent medical physician or psychologist. According to State regulations, a guardianship recommendation must be founded upon a sound clinical basis, and every effort must be made to seek a solution that is the least restrictive possible. The packet contains information on what to expect in court, forms, definitions and concise step-by-step directions. However, it also includes a statement on the benefits of obtaining legal representation.

The packet is available at surrogates' offices and on the Judiciary website: [www.njcourtsonline.com](http://www.njcourtsonline.com).

## Willie Torres Remembered

In March, we were saddened to learn that one of our long-time campers, Wilfredo "Willie" Torres II, 18, had passed away. Willie embodied the spirit of Camp Hope. When he took his first step off the bus on his first day, his smile lit up the campgrounds and his laughter filled the air. He couldn't wait to fill us in on the past year with updates on school and sports. Willie was an avid baseball player with the Challenger League and received a gold medal in bowling at the Special Olympics of 2001 and two bronze medals this year.

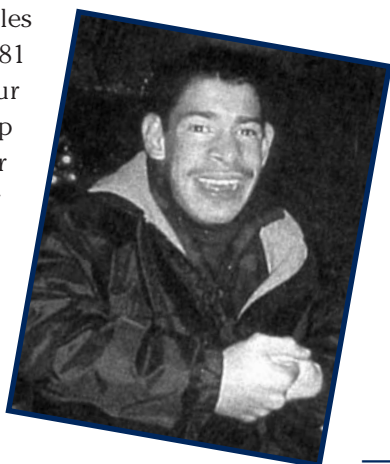


Willie will be greatly missed this summer by both staff and campers. However, in honor of Willie, a mural will be painted near our baseball field, making him a permanent part of Camp Hope. Additionally, employees of International Planning Alliance, LLC, a former employer of Willie's

mother, Carmen Cirilo, will purchase a swing set and a plaque in his memory.

Willie may be gone, but his spirit and zest for life will live on forever in our hearts. His memory will always bring a smile to our faces. We'll miss you deeply, Willie.

If you would like to make a contribution to Camp Hope in Willie's memory, please contact Melissa Soules at (973) 535-1181 extension 1264. Your contributions will help sponsor one of our amazing campers or purchase much needed equipment. Willie's family will be informed of your donation.



## Respite Help... Continued from cover]

to behave as "brats." The reality is, they cannot deal with the sensory input and over-stimulation in that atmosphere. The average citizen finds their unusual behaviors uncomfortable to deal with.

Most families that I know who have special needs kids find it is not worth it to go out in public. Often people judge us wrongly while they are unaware that our child has autism. That extreme frustration makes our situations twice as hard. But, sometimes, we still need our groceries. So we go, knowing what we are in for between our children, and unkind strangers.

Other autistic kids may do things such as self-injurious behaviors, for example. This means they cannot keep from badly hurting themselves. Try to imagine the heartbreak of having your child continually hit his head to the point of bleeding, and, although you do everything in your power to avoid this from happening, it still occurs.



I eventually found Chrissy, a wonderfully gifted helper. With appropriate child care, or trained respite helpers, parents can take time off to get renewed, and most importantly, not stress out about the children's safety. I found ways to go out to parks, and, well, just do some typical things with my boys. That is a really big deal to people like us. Our life has become emotionally healthier since receiving respite help from The ARC of Essex County.

In my first conversation with The ARC of Essex, I mentioned my fractured feet and they immediately got me emergency respite help so that I could find time to heal my feet. I was also able to get time to see a therapist so that I could begin to heal my heart. Then, I was able to take care of all my family's needs better.

I'm hoping that by sharing my personal circumstances, perhaps the public will get an idea of how critical this respite support can be in aiding an entire family with an autistic child. However, the funding for the respite help may be discontinued, thus making our lives even more complex and difficult than they already are.

If anyone is interested in knowing more about the legislature's funding for respite bill, please contact Kathleen Hinnegan-Cohen at The ARC of Essex County, (973) 535-1181, ext.1226.

Julie Pabst, West Caldwell

Reprinted from the "Caldwell Progress."

*Working to build a secure  
financial future for  
The ARC of Essex County*

## OFFICERS

President

Judy Elbaum

First Vice President

Charles Feldman

Second Vice President

George Fiore

Treasurer

Morton A. Plawner

Secretary

Lee Bergman

## TRUSTEES

Thomal L. Abbate

Bruce Bird

Harold Chefitz

Joseph L. Dimino

Barry P. Goldberg

Susan B. Hammer

Stanley Jablonowski

Lois Lautenberg

Barry Lefkowitz

William Sumas

## ADVISORS

Stuart T. Applebaum

Michael J. Franchino, CPA

Peter P. Gorham

Albert C. Ianacone

Kenneth Sauter, Esq.

## Development Department: "Stepping Stones" is a Wonderful Program - How Can I Help?

“Stepping Stones,” our privately funded early intervention program, depends on fundraising events, designated gifts and proceeds from our campaigns to continue program operations. The reputation of “Stepping Stones” is far reaching, and demand is high. Some of our families drive one and a half hours each way to have their children participate.

The Candle Lighters, a group of parents and volunteers, work diligently on two fundraising events each year to generate income that will help meet program expenses. Tricky Tray takes place in February. This year, the second event was Casino Night in May, which had an ad journal.

Our “Stepping Stones” campaign provided additional assistance. I would like to thank the Irving and Blanche Laurie Foundation for the establishment of a scholarship fund to help families enrolled in the early intervention program.

Very often, major donors and donors to our tribute fund specify that they want their contribution earmarked for “Stepping Stones.” We are happy to do that.

In short, there are a variety of ways you can support this program:

- Attend a Candle Lighter Event
- Buy an advertisement in the Candle Lighter's Ad Journal
- Participate in the “Stepping Stones” Campaign
- Designate a major gift or tribute card gift to Stepping Stones
- Support our general campaign, because a portion of that will be allotted to Stepping Stones
- Experience the joy of being a volunteer in the program
- Make a planned gift.

*What is a planned gift? These are a few examples:*

### **Bequests**

*You can leave a specific sum of money or a percentage of your estate or a percentage of the residue to The ARC Foundation or a specific program. This gift will reduce the size of your taxable estate while helping our mission.*

### **Stocks and Publicly Traded Securities**

*The best stocks to give to The ARC are those that have increased greatly in value, particularly those producing a low yield.*

### **Life Insurance**

*If you have a paid-up policy that you no longer require, consider naming either ARC Essex Foundation or The ARC of Essex County as owner and beneficiary. A substantial charitable deduction on your tax returns is possible.*

There is an array of gift-giving options and many ways you can incorporate them into your estate plan. Your lawyer, accountant or insurance advisor can provide you with specific suggestions according to your circumstances and philanthropic goals. Please let us know of your plans. All information will be kept strictly confidential.

Roberta Zweifler, Director of Development, (973) 535-1181, Ext. 1224.

# THE ARC RUN WAS AN INCREDIBLE SUCCESS!

The April 6 ARC Run at Brookdale Park was featured in a wonderful story in The Star Ledger (April 3), which

included an interview with and photograph of Theresa Finnerty. The run was dedicated to the memory of Gino Calvi and Timothy Finnerty, who were lost in the World Trade Center on September 11. At the registration table, we heard people repeatedly say to Theresa,

“We read about you in the newspaper and we want you to know we are with you.”

The 400 participants ranged in age from 7 to 85, and brought in close to \$27,000. We want to thank all of those who participated, made donations or sponsored runners. Our corporate sponsors were Associated Benefit Consultants, Inc., Coldwell Banker Commercial Feist & Feist Realty Corp., Endura FIT, First Union Bank, Kaplow and

Company Insurance, The Guardian Life Insurance Company, Tom Weber at Langdon Ford Financial Group, Bruce Merchant, Miller Advertising Agency and Morgan Stanley.

We received a large donation of food from the Brookdale Shop-Rite in Bloomfield, a \$100 gift certificate from the Livingston Shop-Rite, thanks to ARC Foundation Board member Bill Sumas, and a \$100 gift certificate from Pathmark Stores, Inc.

The 70 volunteers included groups from Bloomfield High School, James Caldwell High School, Montclair High School, The Montclair Kimberley Academy, Prudential Insurance, and

West Orange High School. The Pingry School in Martinsville had a Jeans Day on April 5 and raised \$354 for the race. Our volunteers are to be commended for coming out as early as 6 a.m. on Saturday morning in 30-degree temperatures. It was COLD!!!!!!!!!!!!!!

Our top fund raisers were:

Shawn Cassillo ( <i>Tim Finnerty's nephew</i> ) .....	\$1,100
Emma Calvi ( <i>Gino Calvi's mom</i> ) .....	\$765
Keith Dennig .....	\$750
Gina Stanziale .....	\$750
Mary Tengwall .....	\$500
The Pingry School .....	\$354
Mark Bergman .....	\$350
Lee and Arthur Bergman .....	\$300
Michele Salvadori .....	\$260
Theresa Buckley .....	\$250

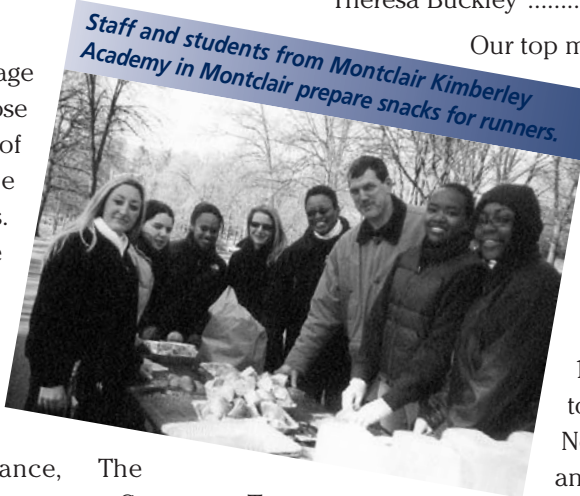
Our top male finisher overall was David Lawlor of McAfee, New Jersey, in 17 minutes and 24 seconds. Our top female finisher overall was Lindsay VanAlstine from Midland Park, New Jersey. Her time was 18 minutes and 24 seconds. Of note was our top finisher in the “Male 70 and Over” category, Joe LaBruno in 27 minutes, 18 seconds. The top “Female in the 60 to 64” category was Anna Thornhill of New York City with a time of 23 minutes and 30 seconds. Our younger runners, who placed first in their age categories,

were Pedro Orday of Morristown, New Jersey, in “Male Ages 14 and Under” with a time of 19 minutes, 40 seconds, and Sara Mouradian of Summit, New Jersey, in “Female Ages 14 and Under” with a time of 24 minutes.

WE CONGRATULATE ALL THE RUNNERS AND WALKERS WHO FINISHED THE RACE!



Students volunteers from Montclair High School try to keep warm

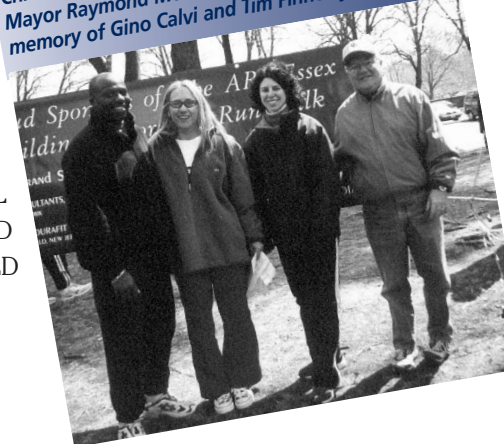


Staff and students from Montclair Kimberley Academy in Montclair prepare snacks for runners.

Jill Perlmutter, a “Stepping Stones” mom, at the finish line.



At the Awards Ceremony, presenters were, left to right, Bloomfield Councilman Bernard Hamilton, Christine Calvi, Theresa Finnerty and Bloomfield Mayor Raymond McCarthy. The race was run in memory of Gino Calvi and Tim Finnerty.



## Tributes

Thank you for so many tributes! Tributes are a beautiful way to acknowledge those you care for, and at the same time, help those in need. To purchase a tribute, please call Diane Yanosh at ext. 1230 or Bernice Engel at ext. 1227.

### **Tributes from February 15, 2002 - May 15, 2002:**

#### **CONGRATULATIONS TO:**

##### **Mr. & Mrs. Peter Gorham on the marriage of their daughter**

Lee & Art Bergman  
Roberta Zweifler

#### **IN HONOR OF:**

##### **Aida & Anthony Birritteri on the birth of their daughter, Isabel Maria**

Jackie Juster

##### **Joanna Dreifus & Sandy**

##### **Weisburst on their engagement**

Lee & Arthur Bergman

##### **Judy Elbaum's special birthday**

Lee & Arthur Bergman  
Roberta Zweifler

##### **The Hasenbein Family on the birth of their son**

Roberta Zweifler

##### **Maureen & John Kudla on the birth of their daughter, Mara Elizabeth**

Jackie Juster

##### **Arthur & Carol Lerner's 50th anniversary**

Kay Hauptman

##### **Pat & Michael Porter's birthdays**

Gilda Sossin

##### **Johanna & Jim Prior's 40th anniversary**

Jackie Juster

##### **Roberta & Walter Zweifler's special birthdays**

Lee & Art Bergman  
Melissa & Jim Loree  
Gordon Ruben  
Lois & Tom Shanker  
Judith & Fred Simon  
Lynne & Howard Wolfe

#### **SPEEDY RECOVERY TO:**

##### **Mort Plawner**

Lee Bergman  
Roberta Zweifler

#### **IN MEMORY OF:**

##### **Father of Bruce Bird**

Lee & Arthur Bergman  
Roberta Zweifler

##### **Gino Calvi**

Deanna & Gary Gammon

##### **Rudolph Cesarini**

Ellen & Herb Lev

##### **Mother of Hal Chefitz**

Roberta Zweifler

##### **Timothy Finnerty**

Irene & Al Cassillo

##### **Father of Roz Hellman**

Bobbie, Walter, David & Jonathan  
Zweifler

##### **Annamae Hession**

Virginia & Dennis Coffey  
Janet & Michael Crowley  
Edmund P. Hennelly  
Nancy & Joseph Howley  
John & Mary Meade  
The Trivigno & Duguid Families

##### **Rev. L.M. McCoy**

Jessie & Stephen McCoy

##### **Thomas Murray**

Roberta Zweifler

##### **William Murray**

Judy & Peter Bellina  
Lee & Arthur Bergman

##### **Father of David Ostheimer**

The Brotman Family

##### **Anne Pilson**

The Zweifler Family

##### **Stanley Schwartz**

Susan & Alan Hammer

##### **Daniel Smith, Sr.**

Frances Smith

##### **Willie Torres**

Brenda Dye  
Employees of International  
Planning Alliance, LLC;  
including:  
Samuel Alleyne  
David R. Alter  
Harvey R. Alter & Assoc.  
Ivor J. Anderson  
Avenius Agency, Inc.

Gerald J. Clericuzio

Judith Panos Clu

R.S. & L.S. Cohen

Monica A. Collaco

Jane Covelli

Mary E. Cromie

Rosalie D'Andrea

Frank M. DeBenedetto

Jeffrey M. Dunst

James & Gail Ellowitch

Brenda S. Feller

Melissa Feller

Robert C. Kievit

Bonnie & David Levitt

Thomas D. Lucia Associates

Diana & Mark Marlow

Cindy & Kenneth Olsen

Salvatore Petruzzellis

Linda O. Pollock

Barbara Reif

Domingo & Johanny Rodriguez

Evelyn & Burton Schneck

Howard A. Udoff

Cherie G. Weening

Susan L. Wolfman

Donald M. Worster

Karen Worster

Dan Cheung Wu & Linda Yuan Wu

##### **Ed Wagner**

Eleanor & Leigh Jones

##### **Kenneth Weber**

Eustace Anselmi

Judy & Pete Bellina

Lee & Arthur Bergman

Barbara B. Best & I. Richard Weiss

Jean Byrne

George & Faith Haskew

Mr. & Mrs. Al Ianacone

Linda Jameism

Sally & Tim Jameison

Natalie Leiter

Livingston P.B.A. Local 263

Courtney & Tom Muoio

Mary & Guy Muoio

Patricia & Kevin Neary

Steve & Licia Pontiakos

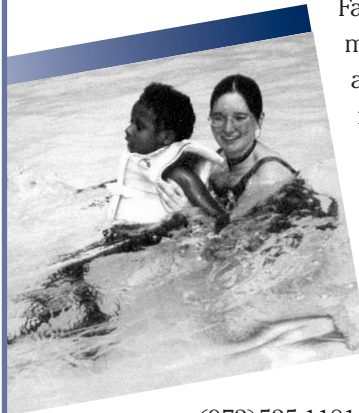
## How Much Do You Know About Special Young Adults (SYA)?

Our Special Young Adults Program in Nutley engages our consumers in volunteer activities that enable them to become involved in their communities and to make a meaningful contribution, under the capable direction of Anne Rotunda, program manager, and Dave Shickel, assistant director of Adult Services. For the last four years, SYA has been helping the Cedar Grove Emergency Squad with the mailing for a donor list. Participants perform various tasks, including paper folding, envelope stuffing, and labeling the envelopes. The Squad saves money by not having to pay a vendor for that service. SYA consumers get a chance to learn some skills, be productive, and feel a sense of accomplishment. The Cedar Grove Squad graciously took everyone in the program to lunch at a local restaurant to show their appreciation for the wonderful work that SYA did.

Another Special Young Adults project is the Companion Club, which pairs consumers with seniors or others with disabilities who need some kind of assistance. SYA members help with things like walking dogs, grocery shopping, doing light work around the house. A lot of very good feelings and companionship develop. Keep up the good work, SYA!

## Family Fun At Camp Hope

Family Swim Days will be held at Camp Hope on four Sundays this summer, July 14, July 28, August 4 and August 11, from 12 noon to 4 p.m. The cost is \$40 for a family of 5 for all four days. Any additional family members will be charged \$2 per Sunday.



Families that enroll may use the pools and picnic facilities. A lifeguard is provided.

Families are responsible for providing their own food and drinks. (No glass containers, please.)

If you would like to enroll, please call Jennifer Salazar at

(973)535-1181 extension 1247. Please be aware

that no refunds will be given for inclement weather, as the camp will be open for indoor recreation.

We hope you will come and enjoy the facilities at Camp Hope. It is a great way to meet other families and beat the heat of the summer.



## The ARC of Essex County Tribute Fund

7 Regent Street, Livingston, New Jersey 07039 • Phone: 973-535-1181, Ext. 1224

Enclosed is my gift of \$ \_\_\_\_\_

In memory of \_\_\_\_\_

In honor of \_\_\_\_\_

To Commemorate Please send acknowledgement to:

\_\_\_ Birthday Name: \_\_\_\_\_

My Name: \_\_\_\_\_

\_\_\_ Wedding Address: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_ Anniversary \_\_\_\_\_

\_\_\_ Retirement \_\_\_\_\_

\_\_\_ Get Well \_\_\_\_\_

\_\_\_ Other: \_\_\_\_\_

Phone: \_\_\_\_\_

Phone: \_\_\_\_\_

Please charge to my VISA/MASTERCARD # \_\_\_\_\_

Expiration Date \_\_\_\_\_ Signature \_\_\_\_\_

If you or your spouse work for a matching gift company, please enclose the appropriate form.



## CASINO NIGHT

*Candle Lighters have done it again!* They produced a successful ad journal and a second wonderful event this year. Nearly 100 people attended Casino Night on May 11 at the Ramada Inn in East Hanover. The food was wonderful (especially dessert); the auction prizes and raffle prizes were great, and of course the gambling was a lot of fun.

Although, the final figures are not in, it is expected that the evening netted about \$35,000. We give thanks to our Ad Journal Co-Chairs, Jill Perlmutter and Christine Eibs Singer; the Casino Night Committee, Ginny Jakimowicz, Leslie Horan, Cheryl Thomas, and Dawn Blomquist, and Elena Glenbowski, and Susan Fuller, and their committees. A job well done!

Ron Carr, the President-elect of the ARC of Essex County, and his wife Vicki stole the show and went home with more prizes than anyone. They were winners of the 50/50 Raffle as well, but returned the money to ARC. We thank Vicki and Ron for their extreme generosity and congratulate them.

## Join The ARC Essex E-Group!

Get our recreation calendar and other announcements by e-mail. Access events calendar, and share news and tips with other family members.

Sign up right on our home page:



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

## SAVE THE DATE

### Wednesday June 19, 2002

Begins at 7:30 p.m.  
Refreshments provided

### ARC Annual Meeting Program

ARC Administrative Office  
7 Regent Street, Livingston

### Monday, September 30, 2002

Registration 10:00 a.m.  
Lunch at 11:00 a.m.  
Golf at 12:30 p.m.  
Cocktails & Dinner at 5:30 p.m.

### Golf Classic XIV

Sponsored by The ARC Essex Foundation  
Rock Spring Country Club  
West Orange

Contact Roberta Zweifler at (973) 535-1181, Ext. 1224

### Sunday October 27, 2002

### Halloween Family Festival

Camp Hope, East Hanover

### Fall 2002

### Bloomingtondale's Shopping Benefit Day

DETAILS TO FOLLOW

### Sunday, November 17, 2002

Special offers  
Door prizes  
Events  
Entertainment

### Magical Night of Giving

New Jersey Gardens Outlet Mall  
Elizabeth, New Jersey  
Tickets are \$5.00

Contact Roberta Zweifler at (973) 535-1181, Ext. 1224

### Thursday, November 21, 2002

Cocktails & Dinner

### Gala Celebration

### "The ARC Family Diaries" Book Launch

Madison Hotel, Morristown

Contact Roberta Zweifler at (973) 535-1181, Ext. 1224

## WANTED

**A POOL TABLE** Please contact the Orange Community Residence, 366 Highland Avenue, Orange (973) 678-3128

### RECREATION ROOM EQUIPMENT - POOL TABLE, PUZZLES, TABLE GAMES, CHAIRS, GAME TABLE, ETC.

Please contact Mozelle Deans at Millburn Group Home, 81 Willow Street, Millburn (973) 376-1628

**VOLUNTEERS** Are you looking for an enriching volunteer experience this summer? You'll find it at Camp Hope, the ARC's summer day camp serving children and adults with developmental disabilities. Camp Hope is located in East Hanover, NJ, and is open from July 1 to August 23. Our CIT (counselor in training) volunteer position is open to anyone 14 years of age or older. The CIT volunteer must be available for at least two full weeks during our camp season and must attend a two-hour orientation on June 6 or June 8. Camp Hope is open from 9 a.m. to 3 p.m. Monday through Friday. (Transportation may be available.) For more information, please call, fax or e-mail us at: Phone (973) 535-1181, extension 1254. Fax (973) 597-0731 E-mail: [Recruitment@arcessex.org](mailto:Recruitment@arcessex.org) Visit us at [www.arcessex.org](http://www.arcessex.org) If you want to work specifically with our Stepping Stones program in Livingston, call Judy Bellina at (973) 992-9830.



7 Regent Street  
Livingston, NJ 07039

Non-Profit Org  
US Postage  
**PAID**  
Permit #70  
Livingston, NJ