

### Three Cheers for...



**Tyler Sutherby**  
by Trina and Jack Lengyel

We are very proud of Tyler for participating in his first holiday program singing “All I want for Christmas is my two front teeth”. With pride, we watched him follow the other first graders, his peers, onto the stage, taking his spot front and center! He was like every other first grader before their song began, waving and saying “Hi Mom! Hi Grandma!”

Tyler’s former paraprofessional had recently shared with me that she had a dream that Tyler sang her a song. I think this was a dream come true, one of our many dreams becoming a reality for Tyler. What a Christmas present! ✂✂



**Yes, There Really is a Best Buddies  
The Best Buddies Program and What it Can  
Do for You**  
by Stephanie Dillworth

Anyone who is close to someone with an intellectual disability knows what it means to try to get that person accepted in some way into an integrated situation. Whether it be a club, sports team, or classroom it is amazing the weight that is lifted knowing your brother, sister, daughter, son has found happiness in a world that didn’t always understand them.

Best Buddies is an international program that helps make these connections possible. Best Buddies was founded in 1989 by Anthony Kennedy Shriver, a name easily recognizable from his mom’s family and his sister, Maria Shriver, wife of the current governor of California and participant in fundraising for Best Buddies.

The mission statement of Best Buddies is to “enhance the lives of people with intellectual disabilities by providing opportunities for one-to-one friendships and integrated employment”, and from my experience, it does a wonderful job.

I got involved in Best Buddies during my sophomore year in college through a program at Grand Valley State University in Allendale, Michigan. My brother has Fragile X Syndrome and I learned quickly that without the connection to the world in which my brother lived, a part of me was not being fulfilled.

Best Buddies plugged me into a wonderful, 17-year-old boy with Down Syndrome. Matching is made through applications that both the buddies and college students fill out. Matches are made based on interests, availability and any other specifications based on the situation. After only one semester, I have already received hearty thanks from his parents who have quickly dropped the obvious nervousness they had at the beginning.

The GVSU chapter has students contact their buddies by phone at least once a week. They hold one-on-one meetings once a month and group outings hosted by the club are also held once a month. These parameters are not set in stone and many buddies end up doing more than is required.

The participants on the college side join up for various reasons but always find a much more fulfilling experience than they ever could have hoped. Many of the students are Special Education majors or Social Work majors who are trying to share experiences with people similar to people they will one day serve. Others were opening themselves up to try to better understand the diverse world they are living in.

Best Buddies is a way for parents to get their children active and participating in experiences out of the house. It is a great opportunity for the kids to hang out with people who are near their own age without their parents around, which provides a great feeling of independence.

Best Buddies does work at the Middle School and High School level along with College and beyond. All it takes is one person willing to take on the challenge and a community willing to support it. Best Buddies is always looking to grow. They just added an e-mail program called e-Buddies that connects friends at an international level while teaching students with intellectual disabilities how to use e-mail in a fun and rewarding way.

Along with GVSU's chapter, there are Best Buddies programs in Michigan at Albion College, Central Michigan University, Eastern Michigan University, Hillsdale College, and University of Michigan.

For more information on the wealth of programs Best Buddies provides, how to contact an existing chapter, or how to start one in your area, visit [www.bestbuddies.org](http://www.bestbuddies.org) or call 1-800-89-BUDDY.

*Stephanie Dillworth is completing her second year at GVSU in the creative writing program. Outside of Best Buddies, Stephanie is constantly reading, enjoying theatre, playing piano, and is involved in the V-Day project on campus. Her family is from Richland, Michigan (near Kalamazoo) and includes parents Wendy and John and 16-year-old Matthew, who has Fragile X Syndrome. ✕✕*

## Through the Maze

### Featured Website

#### [www.Bridges4Kids.org](http://www.Bridges4Kids.org)

**Bridges4Kids** is a non-profit parent organization providing a comprehensive system of information and referral for parents of children from birth through transition to adult life. There is a wealth of information on Bridges4Kids, so much that it could easily consume several newsletters.

Are you looking for services, local support? One of your first stops should be the link "Where to find help for a child in Michigan". Bridges4Kids has resources for every county in Michigan on an easy to click map.

Are you looking for information on respite, childcare, Michigan Positive Behavior Support or summer camps in Michigan? Do you need information on Medicaid, Social Security Income (SSI) or Family Support Subsidy?

Bridges4Kids should be a "favorite" on your web browser. It may easily become the site you visit most often. ✕✕

## Between the Lines

### Featured Book

#### **You Will Dream New Dreams**

Inspiring Personal Stories by Parents of Children with Disabilities

by Stanley D. Klein, Ph.D. and Kim Schive

It's a new year and you may need some new inspiration!

If that's true, the short essays in this book may be the right inspiration to fit into your day. The book can be inspiring for parents who are new to a diagnosis or a good reminder for veteran parents.

It includes the famous piece "Welcome to Holland" by Emily Perl Kingsley.

It also includes one inspiring essay by a mom who has two children; one has a limb deficiency. A repeated phrase throughout the end of her essay is "Forget disability... But never forget."

As the editors state in the book's introduction, the essays help remind us "There is sadness; some dreams are lost. You will mourn, but you can heal. You will be happy again; you will dream new dreams." ✕✕



P.O. Box 1414 ♦ Troy, MI 48099-1414 ♦ 313-381-2834

Our group has grown over the last year and it's time to update/reprint our member directory. The directory lists family contact information and ages of children to enable parents to network with each other. The directory also lists families by city to make networking easier.

If you are currently in our member directory, please review the information in your entry. Has anything changed? Whether or not you want to be in the directory, please share your updated information with us.

In addition, we'd like your input and involvement. Please provide us with comments and suggestions. See the back of this form.

Member Name(s): \_\_\_\_\_

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

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip + 4: \_\_\_\_\_

Telephone (home): \_\_\_\_\_ Telephone (work): \_\_\_\_\_

E-Mail Address: \_\_\_\_\_

Would you like to be included in our member directory?  Yes  No  
Please X one

**Type of Membership:**

Is your membership?  Family  Professional  
Please X one

If professional, please specify your field: \_\_\_\_\_

**If family, please provide information on your children:**

Name	Date of Birth (mm/dd/yyyy)	Do they have FX?	Male	Female
_____	_____	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>
_____	_____	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>
_____	_____	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>
_____	_____	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>
_____	_____	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/>	<input type="checkbox"/>

Can we include children information in our member directory?  Yes  No  
Please X one

Can we list date of birth information on your children? If you wish to list only year of birth please write year in the space to the right. \_\_\_\_\_

Suggestions for future speakers at support meetings: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Suggestions/comments for support meetings: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Suggestions/comments for the quarterly newsletter: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Current committee chairs are provided below. Please indicate if there is a committee (or more than one) in which you are interested in participating:

- |   |                          |
|---|--------------------------|
| Conference Planning, Kim Young  | <input type="checkbox"/> |
| Directories/Newsletters, Sally Nantais                                  | <input type="checkbox"/> |
| Publications, subcommittee of<br>Directories/Newsletters, Sally Nantais | <input type="checkbox"/> |
| Fundraising, Frank Liberati   | <input type="checkbox"/> |
| Meeting Planning, Arlene Cohen  | <input type="checkbox"/> |
| Parent Liaison, Nina Liberati   | <input type="checkbox"/> |
| Library Resources, Mary Beth Langan                                     | <input type="checkbox"/> |
| IEP Advocacy/Resource, Kim Young  | <input type="checkbox"/> |
| NFXF Liaison, Arlene Cohen  | <input type="checkbox"/> |
| Publicity, Mary Beth Langan   | <input type="checkbox"/> |
| Executive Board Procurement, Kevin Dacey                                | <input type="checkbox"/> |
| Website, Nina Liberati  | <input type="checkbox"/> |

Please share your updated information and important comments with us by mailing this form to the FXAM P.O. Box on front of this form or emailing or calling Mary Beth or Sally by March 15, 2006.

Mary Beth, 313-881-3340, [mblangan@hotmail.com](mailto:mblangan@hotmail.com)  
Sally, 734-282-7910, [sally\\_nada@juno.com](mailto:sally_nada@juno.com)

## From the President's Desk

By Laureen Majeske

As the New Year begins, I've reflected on all that we have accomplished in the past year and it is exciting to look ahead to the coming year. Plans for 2006 include a continuation of our Support Group Meetings (with some interesting and informational guest speakers), bowling, golfing, family events, new fundraising ideas and the International Fragile X Conference in Atlanta this July. Congratulations to our newsletter editing team on their one-year anniversary of eXtra, eXtra and thanks to all of you who have participated by contributing articles and ideas.

At the March meeting, we will be holding elections of officers for the Executive Board. If anyone is interested in a position as an officer or as a member of the Board of Directors, please let me know by the February meeting. I will provide you with all of the details. This is a great opportunity to become more involved and assist in fulfilling our mission:

The **Fragile X Association of Michigan** unites the fragile X community to:

Enrich lives through educational and emotional support,

Promote public and professional awareness, and

Advance research toward improved treatments and a cure for fragile X syndrome. XX

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From the bylaws (Directors and Officers of FXAM):

### ARTICLE 5. DIRECTORS

#### SECTION 1. NUMBER

The corporation shall have not less than eleven (7) Directors nor more than fifteen (15). The number of Directors may be changed by amendment of this Bylaw at any regular or special meeting of the Board of Directors or as otherwise provided for by amendment of these bylaws.

#### SECTION 2. TERMS OF DIRECTORS

Each Director shall, at the time of approval of these Bylaws, serve a two year term commencing immediately but running from January 1 next subsequent to approval (i.e. if Bylaws approved 12/15/2004 then term would run 12/15/2004 through 12/31/06. Said term, upon expiration, can be extended

by majority vote of the Board in session with a quorum (see Sections 13 and 14). There is no limit to how many terms a particular Director may serve but the Board, as a whole, shall be mindful of the need to change Directors from time to time so as to generate interest in the Fragile X community in Board service and to maintain, to the extent possible, some geographic balance to the Board for what is a statewide organization.

### ARTICLE 6. OFFICERS

#### SECTION 1. NUMBERS OF OFFICERS

The officers of the corporation shall be a President, Vice President, Secretary, and a Chief Financial Officer who shall be designated the Treasurer. Any number of offices may be held by the same person except that neither the Secretary nor the Treasurer may serve as the President or Chairperson of the Board except, as allowed and approved by majority vote at a regular or special meeting of the Board where both the President and Vice President are absent.

#### SECTION 2. QUALIFICATION, ELECTION, AND TERM OF OFFICE

Any Director may serve as an officer of this corporation. Officers shall be elected by the Board of Directors, at any time, and each officer shall hold office until he or she resigns or is removed or is otherwise disqualified to serve, or until his or her successor shall be elected and qualified, whichever occurs first.

#### SECTION 3. SUBORDINATE OFFICERS

The Board of Directors may appoint such other officers or agents as it may deem desirable, and such officers shall serve such terms, have such authority, and perform such duties as may be prescribed from time to time by the Board of Directors. XX

*Quote for the Quarter*

To accomplish great things,  
we must dream as well as act.

*Anatole France*

## Mark Your Calendar

### Support Meetings:

**When:** February, March and April  
First Saturday of the month.

**Time:** Business Meeting: 6 – 7 p.m.  
Support Meeting: 7 – 9 p.m.

**Where:** Beaumont Hospital, Royal Oak  
Admin Building, Private Dining Room

### Guest Speakers/Special Events:

**Feb 4: Guest Speaker from MPAS**  
“IDEA 2004 – How it affects Students  
with Disabilities”

Electronic copies of our newsletter are available on our website. If you would like to share them with family, friends or professionals, please share our web address with them.

### Contact Information:

Phone: 313-381-2834

E-Mail: [fraxmich@hotmail.com](mailto:fraxmich@hotmail.com)

Web: [www.Fragilex.org/html/michigan.htm](http://www.Fragilex.org/html/michigan.htm)

*eXtra, eXtra*

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