Time to Plan for Summer Camp

Dear parents,

My name is David Jensen and I want you to know, I loved the Epilepsy Foundation’s Jason Fleishman Summer Camp - because you know you are not alone. Every camper has epilepsy so if your child has a seizure you don’t have to worry about other kids freaking out. All the counselors there are very experienced and will know what to do if your child has a seizure.

I go back to Epilepsy Camp every year because it is so much fun. Each day we do a different activity. We go horseback riding and canoeing. The group goes to the Kiva which is a recreation center. We get to do archery and rock climbing and much, much more.

David at the 2006 Summer Camp

At Epilepsy Camp everyone is just like you and you can be yourself. I hope I get to meet your child there this year. Also, you can sponsor a lucky camper by supporting the upcoming Seafood and Sandal fund raiser on June 1. I’ll be there!

Sincerely,

David Jensen

17 years old

and a longtime Summer Camp veteran

see page 7 for more information about the Summer Camp
“On race day our strength will be in numbers.”
- John Keating
Event Chairman, Strides for Epilepsy

575 walkers and runners joined the Epilepsy Foundation of Colorado at Washington Park in Denver for the 3rd annual Strides for Epilepsy 5K Walk/Run. Under the leadership of chairman John Keating, the event tripled in size.

Over $50,000 was raised to support the programs and services provided by the Foundation. John and his wife Dana are particularly vested in creating strong awareness for epilepsy and its challenges because their four year old daughter, Charlotte was diagnosed with epilepsy at four months. The Louisville Fire Department (pictured), has made many trips to the Keating home to attend to Charlotte during severe seizures. They attended the event in full force and their cadence during the run, “We run for epilepsy, we run for Charlotte”, was a moving moment.

Thank you to the entire event committee: John Keating, Jamie Jacobs, Ed Maa, M.D., Bob Pinkerton, BJ Wakely, BKB, Ltd and sponsors P&G Exhibits, PromoTech, Navicor and Pharma. Also, thank-you to our in-kind donors Mix 1, Clif Bars, AquaFina and Starbucks. A special thanks to Dr. James Rouse for his inspiring words at the start line!

Surrounded by their good friends, the Louisville Fire Department, John Keating, event chairman, daughter Charlotte and wife Dana enjoy the success of Strides for Epilepsy 5k Walk Run

<table>
<thead>
<tr>
<th>Strides for Epilepsy Teams</th>
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<tbody>
<tr>
<td>&quot;Walk On&quot; says Kaymen</td>
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<td>A&amp;A</td>
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<td>Amber Stohner</td>
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<td>Aquafina</td>
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<td>Bovmeisters</td>
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<td>CAC Warriors</td>
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<td>Cameron Morton</td>
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<td>Children’s Neurology</td>
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<td>Claire’s Superstars (#1 Fundraiser)</td>
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<td>Clif Bar</td>
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<td>Convulsion Consciousness</td>
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<td>Dignity Walkers</td>
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<td>EFCO</td>
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<td>Erica James</td>
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<td>Go Broncos</td>
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<tr>
<td>Heather Middleton</td>
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<td>Johns Manville</td>
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<tr>
<td>Team Joseph</td>
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<tr>
<td>Kaymen’s Walkers</td>
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<td>Lily Cannon &quot;Boom &amp; Down&quot;</td>
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<td>Longmont Fire</td>
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<td>Lorene Devine</td>
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<td>Louisville Fire</td>
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<td>Mckenna’s Team</td>
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<td>Mix 1</td>
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<tr>
<td>Morgan’s Quest</td>
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<td>Mover’s &amp; Shakers</td>
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Dear Friends,

As your board president, I appreciate this opportunity to share a few thoughts with you regarding the direction of the Epilepsy Foundation of Colorado (EFCO).

We all know, for many years there was a stigma attached to breast cancer, aids and alzheimers - the same stigma we are still living with for people who have epilepsy. It is time to break down these barriers and open up doors of opportunity and quality of life. Today is the beginning of new efforts within all realms of the good work that has been accomplished by EFCO over the years, and the work that still needs to be done.

Over the past year, we have seen many changes. We have a new Executive Director, Gail Pundt. Gail has been a part of Colorado’s non-profit community for over thirty years and has served in senior management positions for worthwhile organizations including Special Olympics of Colorado, United Cerebral Palsy and Centura Healthcare. Her energy, enthusiasm and experience within non-profits are great attributes for the work we need to accomplish in the coming years.

This past winter, the board of directors and staff held a strategic planning meeting that emphasized evaluation and development of premiere statewide services for people with epilepsy and their families.

Six major areas were identified for focus over this next year:
1. Board Development to strengthen the organization as a whole;
2. Statewide Information and Referral that is consistent, easily accessible and bi-lingual;
3. A stronger statewide network of Support Groups based on community need;
4. Assessment of existing programs to expand those that qualify as necessary statewide resources;
5. Targeted expansion of EFCO’s funding base; and
6. Advocacy.

We look forward to keeping you updated as the structure to each of these priorities unfolds.

Our ultimate goal through this planning process is to be a meaningful resource to people who have epilepsy and their families. The work has just begun and we look forward to your input.

It is an honor to serve as your board president and I would like to thank the board of directors, community partners, staff and many volunteers who make the Epilepsy Foundation of Colorado such an important part of the epilepsy family.

Sincerely,

Kathleen Welker
Kathy Welker, Board President

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On February 6, the Denver Police Academy received training by Dr. Mark Spitz regarding epileptic seizures and “best practices” for appropriate response and first aid. Dr. Spitz is a well known epileptologist at the University of Colorado Health Sciences, a member of the EFCO’s Professional Advisory Board and one of the founders of the “First Responders Seizure Trauma Program”. Law enforcement need to make split second decisions to assure the safety of individuals, the community and themselves.

Without the right information, some types of seizures can be misdiagnosed. Knowing how to identify and respond to the wide variety of seizures that can occur is critical.

To schedule a training for your law enforcement personnel, fire department or medical response team, please contact Marcee Peterson at 303-377-9774.
These articles were recently acquired by the Epilepsy Foundation of America National Library. To access this information, go to www.epilepsyfoundation.com. Type “National Epilepsy Library” in the search box. Or if you don't have access to the internet, please call our Statewide Toll Free Number 1-888-378-9779 and we will print and mail you this information.


Epilepsy and women's health issues: Unmet needs - survey results from women with epilepsy. Epilepsy Behavior

Reproductive endocrine function in women with epilepsy: The role of epilepsy type and medication. Epilepsy Behav. 2007; 10(1):77-83. Lofgren E, Mikkonen K, Tolonen U, et al


Mortality and morbidity rates are increased in people with epilepsy: Is stress part of the equation? Epilepsy Behav. 2007; 10(1):1-7 Yuen AW, Thompson PI, Flugel D, et al


Quality of life in young adults with uncomplicated epilepsy. Epilepsy Behav. 2007; 10(1):142-7. Raty LK, Wilde Larsson BM


People with epilepsy are often perceived as violent. Epilepsy Behav. 2007; 10(1):69-76 Kate Collins TB, Camfield PR, Camfield CS, et al


Factors associated with employment in epilepsy patients. Epilepsy Behav. 2007; 10(1):89-95 Bautista RE, Wludyka P


Dated, March 9, 2007
The Strength of our Organization

At the Epilepsy Foundation of Colorado, we are honored to work with so many dedicated and talented medical professionals who are truly invested in the field of epilepsy. In fact, not only do these wonderful individuals work tirelessly during the day, but they also go the extra mile by volunteering for the EFCO.

We would like to take this opportunity to thank our Professional Advisory Board (PAB), who guide us through decisions that help to assure strong programs and initiatives for people with epilepsy, who take the time to talk individually to our clients and their loved ones about the impact of people who live with seizures, and who take time to provide insightful education at our many conferences and seminars throughout the year.

A most gracious and heartfelt thanks to the Epilepsy Foundation of Colorado Professional Advisory Board:

- Tom Reiley, MD, MHS, Chairman
- Ed Maa, MD, Chairman Elect
- Rhonda DeBello, RN, Secretary
- Jacci Bainbridge, Pharm. D.
- Lauren Frey, MD
- Sheri Friedman, MD
- Brain Grabert, MD
- Carol Hennessey, RN
- Peggy Hugger, RN
- James Kelly, MD
- Debra Kirsten
- Kelly Knupp, MD
- Pramote Lauprasert, MD
- Paul Levisohn, MD
- Barbara Phillips, MD
- Mark Spitz, MD
- Laura Strom, MD
- Asha Sunku, MD
- Alan Zacharias, MD

Parent Tip

If your child with epilepsy receives any type of Medicaid benefit, it may be possible to become your child’s Certified Nursing Assistant (CNA) and earn an hourly wage every day, seven days each week, for the amount of hours your child is deemed eligible. This number is designated by a Home Health Care organization through an evaluation process.

Epilepsy can have a high, negative impact on a family’s income potential. Becoming a CNA may be one way to recoup lost income or generate new income for your family. Call your child’s case manager for more information.

DONATION CENTER

Please donate your gently used clothes and household appliances.

To schedule a Pick-Up, please call

303-428-5600
Support Group Dates and Meetings

When epilepsy is diagnosed, it affects the whole family. Many people and their families who are living with epilepsy report a need for support and education within the epilepsy community. Support groups provide this to those who are interested in connecting with others living with epilepsy. Below are the Epilepsy Support Groups throughout Colorado.

### ADULT CLIENTS:

<table>
<thead>
<tr>
<th>Location</th>
<th>Date and Time</th>
<th>Details</th>
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<tbody>
<tr>
<td><strong>Aurora</strong></td>
<td>3rd Tuesday of the month 3:00pm</td>
<td>Contact: Marcee Peterson · 303-377-9774</td>
</tr>
<tr>
<td><strong>Boulder</strong></td>
<td>2nd Wednesday of the month 7:00pm</td>
<td>Various Restaurants in Boulder</td>
</tr>
<tr>
<td><strong>Colorado Springs</strong></td>
<td>3rd Tuesday of the month 5:30pm</td>
<td>Contact: Veronica Valdez · 719-583-8233</td>
</tr>
<tr>
<td><strong>Denver</strong></td>
<td>Adult Surgery Clients</td>
<td>3rd Wednesday of the month UCHSC Fitzsimons Campus 5th Floor Conference Room Contact: Rhonda DeBello, RN · 720 848-2133</td>
</tr>
<tr>
<td><strong>Englewood</strong></td>
<td>3rd Tuesday of the month 6:00pm</td>
<td>Swedish Hospital Conference Center 701 E Hampden Ave Englewood, CO 80113</td>
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### PARENTS:

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<tr>
<th>Location</th>
<th>Date and Time</th>
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<tbody>
<tr>
<td><strong>Colorado Springs</strong></td>
<td>3rd Thursday of the month 6:00pm</td>
<td>Community Partnership for Child Development 2330 Robinson Street Colorado Springs, CO 80904 Contact: Heather Jackson · 719-491-7340</td>
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### CLIENTS/PARENTS:

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<th>Date and Time</th>
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<tr>
<td><strong>Greeley</strong></td>
<td>Adult Clients &amp; Parents</td>
<td>1st Monday of the month 7:00pm First Congregational Church 2101 16th Street Greeley, CO 80631 Contact: Allison Sedlacek · 970-978-0022</td>
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### CLIENTS/PARENTS:

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<tr>
<td><strong>Denver</strong></td>
<td>Last Tuesday of the month 5:30pm</td>
<td>Epilepsy Foundation of CO 234 Columbine Street, Ste 333 Denver, CO 80206 Contact: Marcee Peterson · 303-377-9774</td>
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### YOUNG ADULT CLIENTS:

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<th>Location</th>
<th>Date and Time</th>
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<tr>
<td><strong>Denver/CU</strong></td>
<td>ages 18-27</td>
<td>2nd Tuesday of the month 4:30pm University of Colorado Denver Auraria Campus</td>
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Tivoli Student Union, Ste 320 900 Auraria Pkwy Denver, CO 80204 Contact: Marcee Peterson · 303-377-9774

### YOUTH:

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<tr>
<th>Location</th>
<th>Details</th>
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<tbody>
<tr>
<td><strong>Denver</strong></td>
<td>Youth Bowling Night (ages 11-17), Quarterly every 2nd Monday of the month 5:30pm Elitch Lanes Bowling Center 3825 Tennyson Street Denver, CO 80212 Contact: Marcee Peterson · 303-377-9774</td>
</tr>
</tbody>
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Have you Ever Wondered What Our Logo Means?

- The light of understanding
- A lifeline for 43,000 Coloradons living with epilepsy
- The light of research leading us to a cure

Please help us keep the flame burning bright!
Knowledge Is Power
Generic Substitution

Did you know it is extremely important that you contact your doctor before considering a switch to a generic substitution if you are currently on a brand name medication. Pharmacists cannot and should not suggest a generic drug unless you have written prior approval from your physician. Also, be sure your physician writes “DAW” (Dispense as written) on all your prescriptions to avoid a substitution.

If you have achieved control of your epilepsy by use of a name brand medication, pharmacists must dispense that name-brand drug; if you do well on a generic, you must receive the same generic from the same supplier as usual. Before ANY substitutions can be made, the prescribing physician and the patient must be notified and give consent.

In some cases, a neurologist knows that their patient only does well on a name-brand epilepsy medicine. This happens when the patient has a narrow therapeutic window. They require a very specific amount to control their seizures and if they go over this level or under this level they become toxic. The controlled dose may only be available by taking a name-brand formulation, which is exactly the same every time you purchase it. Generics are not required to be bioequivalent to name brands, so receiving a generic substitution could upset the delicate seizure control of someone who has a narrow therapeutic range.

This is not to say that some patients don’t do well on a generic. But this is a discussion and decision you and your physician should make.

Why you may ask, would anyone tinker with the medicine that someone takes for his or her epilepsy? In the environment of spiraling costs, health care provider groups struggle to find creative strategies to control these rising costs. One such strategy is to create incentives for the use of generic medications, which are less expensive than their name-brand counterparts. Physicians feel this pressure to prescribe generics over name brands, insurance providers promote generics by requiring higher co-pays for name brands, and even government sponsored health programs like Medicaid reimburse pharmacists at a higher rate for generics, to encourage substitutions whenever possible.

We want to make sure legislators understand the issues behind substitutions. If you have had a negative reaction to a generic substitution medication and your experience can be verified by your physician, please let us know. Call 303-377-9774.

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Information at your Fingertips

EFCO staff respond to over 1,000 information and referral calls annually. The wide variety of needs range from discount programs for medications, support groups, parent to parent connections, legal matters and so much more.

In 2007 it is our goal to make this information easily accessible to our customers.

- **EFCO Statewide Toll Free Number:** 1-888-378-9779
- Partnership for Prescription Assistance
  www.pparx.org · 1-888-4PPA-NOW
- Peak Parent Center
  www.peakparent.org · 719-531-9400
- Family Voices of Colorado
  www.familyvoicesco.org · 1-800-881-8272
- EMPOWER Colorado
  www.empowercolorado.org · 1-866-213-4631
- Parent to Parent of Colorado
  www.p2p-co.org · 1-877-472-7201
- The Legal Center for People with Disabilities
  www.thelegalcenter.org · 303-722-0300
- Canine Assistance
  www.canineassistance.org · 1-800-771-7221
- Mile High United Way
  www.211colorado.org · 303-561-2111

2-1-1 is the national abbreviated dialing code for free access to health and human services information and referral.

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The Jason Fleishman Summer Camp

Cover Story continued

Youngsters attending Summer Camp see David as a role model - an opportunity to focus on what they CAN do. And, David is right - campers can participate in a whole spectrum of activities in a safe, caring environment.

Four registered nurses are on site at all times and all counselors are trained and seasoned. We maintain a counselor/camper ratio of 1 to 5. The camp is geared to youth, ages ten to seventeen. For some parents, this is the first time their child has been away from home. We have heard again and again, it’s a good growing, learning experience for Mom and Dad too.

Camp is scheduled for **July 22 through 26** at Snow Mountain Ranch. For more information contact our main office at 303-377-9774 or our website at www.epilepsycolorado.org. The cost is $300 per camper and full scholarships are available.

We look forward to enjoying the company of your child!

Gail Pundsack
Executive Director