



# Fundraising Resource Guide

Batten Disease Support &  
Research Association





**BATTEN  
DISEASE**  
SUPPORT & RESEARCH  
ASSOCIATION  
A LIGHT IN A WORLD OF DARKNESS



Lance Johnston  
Executive Director



Adina Ryan  
Director of Development

## Message from our Directors

### THANK YOU!

Thank you for supporting the Batten Disease Support and Research Association. Your dedication to the organization and its mission is what keeps us going strong. Your fundraiser is a valuable part of our ongoing effort to support families, fund research, and find a cure. Hope is on the horizon toward finding a cure, but we need you. Without the hard work and dedication from families like yours, BDSRA would not exist. You *can*, and *do*, make a difference in the lives of everyone touched by Batten disease by helping to raise money and awareness of the disease.

### WE ARE HERE TO HELP YOU

Included in this packet you will find ideas, tips, and guidance on how to get the most out of your event. Please use these tools to help support your efforts. No event or idea is too big or small. We will help you along the way and provide you with the assistance you need. Also, please feel free to customize the tools to fit you, and your event. We look forward to working with you and to hearing your fundraising success stories!

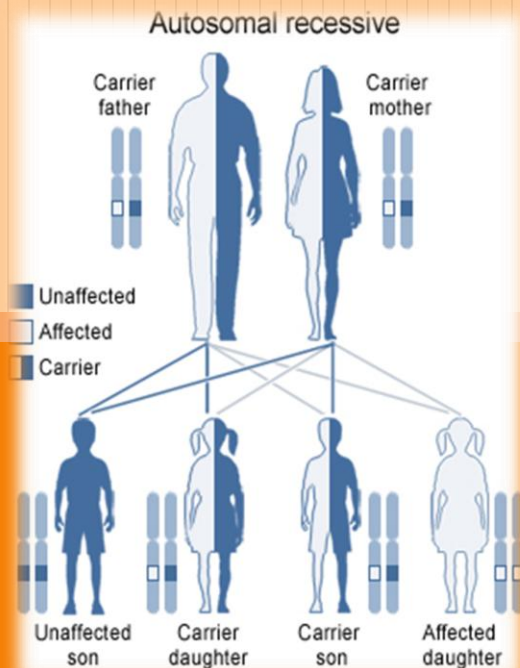
Please visit our website at [www.bdsra.org](http://www.bdsra.org) or contact Adina Ryan at [aryan@bdsra.org](mailto:aryan@bdsra.org) or at 866-287-7233 for additional information or questions.

You can feel secure knowing that BDSRA is an upstanding non-profit organization. Our 990 tax forms and annual audit can be found on the BDSRA website and on Guidestar ([www.guidestar.org](http://www.guidestar.org)).

BDSRA is a 501(c)(3) non-profit charitable organization as recognized by the Internal Revenue Service with main headquarters in Reynoldsburg, Ohio. Our EIN number for tax-deductible donations is 91-1397792.

**Your support helps to make a difference in the life of a child with Batten disease. Every week a child is diagnosed with Batten disease, and every week another family is changed forever.**

# Facts about Batten Disease



Batten disease is a genetic brain disease that primarily strikes children. Presently, there is no treatment; there is no cure.

It is always fatal.

## What is Batten disease?

Batten disease is a neurodegenerative disease that primarily affects children between infancy and school age. There are more than 10 forms of the disease. Batten disease is the common name for a group of diseases known as neuronal ceroid lipofuscinosis (NCL).

## How common is it?

Batten disease is relatively rare, occurring in an estimated two to four of every 100,000 births in the United States. There are currently 500 children living with Batten disease in the U.S. and Canada alone.

## What are the common forms of Batten disease?

There are four main forms. The symptoms of each form are similar, but the age of onset and rate of progression vary.

- *Infantile NCL* begins before the age of two and progresses the most quickly of all the forms of Batten disease. Affected children generally live into their mid-childhood years.
- *Late Infantile NCL* begins between two and four years of age. Early signs typically include loss of muscle coordination, seizures, as well as progressive mental deterioration. This form progresses rapidly and usually ends in death between ages eight and twelve.
- *Juvenile NCL* begins between the ages of five and eight. Early signs include progressive vision loss, seizures, ataxia and clumsiness. This form progresses relatively slowly and ends in death when affected children are in their late teens or early 20's, though some may live much longer.
- *Adult NCL (Kuf's or Parry's disease)* usually begins before the age of 40, causes milder symptoms that progress slowly and does not cause blindness. Adult NCL does shorten life expectancy, though the lifespan of affected individuals varies widely.



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# Facts about BDSRA

BDSRA is a 501(c)3 non-profit charitable organization recognized by the IRS and headquartered in Reynoldsburg, Ohio.

BDSRA is the only family support organization in the United States, Canada, New Zealand, Australia, Spain, South America and South Africa which is specific to Batten disease.

- BDSRA is the leading international presence in Batten disease education, family support, advocacy and research.
- BDSRA is the largest private source of funds for international research on Batten disease. Since our founding in 1987, BDSRA has funded more than \$3.5 million worth of scientific research.
- BDSRA was formed in 1987, by parents of three children with Batten disease in an effort to provide support for parents, provide education about the disease, and act as a national registry for NCL researchers around the world.
- BDSRA maintains a comprehensive clinical database of children and their families living with Batten disease. More than 1,200 families are currently registered.
- BDSRA organizes and sponsors the annual Batten Disease Family Conference which provides continuing educational and networking opportunities to parents and other family members, teachers, scientists, physicians, and others involved in the care of a child with Batten disease. Each year the conference is held in a different location across the U.S.
- BDSRA publishes a variety of materials and maintains an active website designed to help provide accurate and the most current information to families and others interested in this disease.
- BDSRA directs over 89% of each dollar toward programs and services to directly support families.
- Nearly 96% of BDSRA revenue annually is derived from private donations and fundraisers being held across the country by family, friends, and other supporters.



## Basic Principles of Fundraising

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- **People give to people, not causes.** There are thousands of good causes out there and most people tend to give because someone they know is affected, involved, or a friend recommended it. *Remember that you are asking someone to help children who are dying with a horrible, fatal neurological disease, not for yourself.*
- **Underdogs may be popular in sports, but not in fundraising.** People give to worthwhile and successful organizations. Organizations that are well run and doing important work. You should feel that you are providing the donors with an opportunity to support a serious mission.
- **You can't get money if you don't ask for it.** There are very few people who will send money unsolicited. Even if you tell them you are raising money for an important cause, but forget to ask for a donation, the chances are pretty good that you will not receive a donation.
- **Make your gift first and ask in person.** Always make your own gift first. Your own contribution gives credibility when you ask someone else. Whenever possible, it is always better to ask for a donation in person rather than by telephone or mail. If you do use a mailing campaign, be certain to follow up either by phone or in person.
- **Ask for a specific amount.** People like to know what is expected of them. Try to determine in advance the appropriate amount to ask a donor to give, but remember if you ask for \$10 and they were thinking \$100, you are likely to get \$10. Most people are not insulted, and will either say no, or offer something smaller if it is more than they can do. (Always say yes to a smaller donation – don't argue for more)
- **Don't apologize and don't take "No" personally.** Most individuals and businesses make donations to people they know and to worthy causes, so don't apologize for asking. Simply express the importance of this mission with them. If they do say no, remember it is not about you. People are going to say no sometimes for all kinds of reasons. You should never make them feel bad about saying no, but do make sure they are not saying "not now" or I need more time to decide.
- **Thank you, thank you, thank you.** Whether you receive a donation or not, you should also thank the individual for their time to listen to your cause. How you treat them now will determine whether they will give to you again in the future. It is important to thank them personally, quickly, and repeatedly. Keeping them in the loop with information about the success of your event and recognizing them in any printed materials.



## Planning a Successful Event

Planning an event is indeed a great deal of work, but as you develop the basics and formulate a plan, it gets easier. Proper planning will keep your fundraiser from becoming an overwhelming task. Remember you are not in this alone, and others before you have already helped pave the way to your success. BDSRA is also committed to support you in any way possible. We are here, ready and eager to help. We welcome your call and look forward to assisting you.

### *Celebrate Lives*

Most events are a celebration of all the children who have endured Batten disease. While raising money is your primary goal, make sure you have fun while doing it. This guide is intended to provide you with a variety of ideas and strategies that will guide you as you plan your important fundraising events.

### *Determine your target audience and location.*

No event is too big or too small as long as you can communicate clearly that all your profits are going to support a great cause. Who are you targeting to attend? Consider ages and appropriate activities. Make certain your audience will feel this is a worthwhile event to attend and invest money in.

### *Outline a plan and a budget*

Like any major activity, you'll need a basic outline of your fundraising event. This is the time to think of all questions you will need to answer. What type of event do I want to hold? What time of year? How much money can I spend? Do I want an informal or formal event? All of these are important questions and the answers must come in the pre-planning stage. Think about what you can do to make the biggest impact. Remember, not everyone can pull off a multi-million dollar fundraising event their first time out. Work with the resources around you and **DO SOMETHING YOU LOVE!**

### *Rally the troops!*

Since a fundraising event can be quite an undertaking, why not gather a few of your friends and family as volunteers to help you pull it off? If two brains are better than one, imagine what a group of 5 brains can think up. This group of people will also be there to support you throughout every stage of the fundraising process. They can also help you spread the word about your fundraiser and help you gain even more support.

### *Delegate Responsibilities*

After "rallying your troops", you need to clearly define each person's role for the fundraiser. Do you need someone to man a table to sell raffle tickets, handle concessions, or be greeters for your event? Don't underestimate the last minute needs for even minor tasks.

### *Determine your objectives*

Now that you have formed a group, collectively decide what you hope to achieve through your fundraiser. These objectives can be as broad as "Raise \$5,000" or as specific as "Recruit TV broadcaster Hannah Jones to cover our event." Make sure to keep an open mind and think about all the different outcomes of fundraising (raising money, awareness, more fundraising events, press time, etc). Determining your objectives will also help you better delegate the tasks at hand.

### *Stretch your dollar*

The goal of any fundraiser is to raise money for a particular cause. However, every good fundraiser needs a little money to get things moving. Most people will subtract these costs from their grand total when figuring the amount of money raised (*see our budget template*). If you want to raise more money, you'll need to reduce your costs. Having things donated like food, beverages, t-shirts, services, and venues will

greatly help reduce your costs. You may want to ask local corporations if they can sponsor your event. (see samples of corporate sponsor letters at the end of this guide)

### ***Making your work, work for you***

How many times have you been asked to buy Girl Scout cookies or Boy Scout popcorn from co-workers at your job? Your co-workers and employer can be a huge fundraising resource. Many companies have a “matching gift” program where they will match the dollar amount raised by an employee. This is also a great way to find a corporate sponsor.

### ***Spread the word!***

Now that you know the specifics, it’s time to start telling everyone you know about your event. Create a flyer to post around town. Take your flyer to the local bowling alley, bank, grocery store, etc. and be sure to ask permission before hanging up your flyer. Ask local churches if they would be willing to put your event information in their weekly bulletin. Create a press release to send to local newspaper, television, and radio stations (see samples). Don’t forget to put a contact name, phone number or email on the flyer in case people have questions. Consider promotion through mass email, a Facebook invite, or other social media outlet. Sharing information through a variety of mediums is important to ensure it is well attended.

### ***Different ways to donate***

Not everyone will be able to attend your event. It’s important to let people know the different ways they can help make a difference. Create a website for your event with on-line donation capability. Provide the address to BDSRA so people can send their donation directly to us. Create a “No Show” flyer for your event for people who just can’t make it. Make sure to include raffles, silent auctions, or games at your event to help raise extra funds. The possibilities are endless but the result will always be positive.

### ***Mind your manners***

Don’t forget to thank all of your attendees, donors, and event volunteers for their help and dedication. This should be done before, during, and after your event. Make a few general announcements during the event to recognize key sponsors and supporters. Make sure to write a follow-up thank you letter to those who participated. You may also want to include the successes you achieved during the event to help those who participated feel like they made a real difference. If you thank them now, they’re more likely to help you again in the future.

### ***Sending your donation***

Make sure that all donations are made payable to BDSRA. Remember to tell your supporters that they can donate to BDSRA through our website: [www.bdsra.org](http://www.bdsra.org). We accept cash, credit and money order donations. Be sure to send all donations to:

**Batten Disease Support & Research Association  
166 Humphries Drive  
Reynoldsburg, OH 43068**

### ***What can BDSRA do to help in your fundraising activities?***

As always, BDSRA is here to help you. Besides general assistance and information for your fundraiser we can provide you with the following:

- Brochures
- PSA (Public Service Announcements) and Videos
- Banners and table display
- Logos, letterhead, and photos
- Credit card machine and slips
- Promotional items: awareness bracelets, magnets, lapel pins, brochure bags and other items on special request. (Please make special order requests 6-8 weeks in advance) These are provided on a donation basis for those doing fundraisers for BDSRA.

**We kindly request that you mention the BDSRA website and/or mission statement on any brochures, flyers, or signs that you may create and how the funds from your event will be used (research, operations, conference, programs, etc).**



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## Fundraising Event Ideas

Still not sure you can pull off a successful fundraiser? Here are a number of ideas to get you started. The number of fundraising ideas is endless. The most important thing to remember is that a fundraiser should be enjoyable for you and those helping you. With so many unique ideas, you should have no problem creating a fundraiser to suit you and your community. Some fundraisers require a lot of preparation and work while some require simply spreading the word. There is no fundraiser too big or too small!

The list below is meant to inspire you and give you a few ideas. If you like something on the list, feel free to use it. We have even created some **Fundraisers in a Box (FIB)** for some of the most common events:

- **Golf Outings**
- **Walk-A-Thon or 5K Run**
- **Barkin' For Batten Dog Walk**
- **Poker Run**
- **Black Tie Gala**
- **Wine Tasting**
- **Trivia Night**
- **Letter (E-Letter) Campaign**

You may download these special guides through our website [www.bdsra.org](http://www.bdsra.org) or contact Adina Ryan at 866-287-7233 to have a copy sent to you.

The sky is the limit! Be creative, original and most importantly, HAVE FUN!

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### *Annual Golf Tournament (FIB)*

Golf tournaments have been successful in raising substantial funds for BDSRA and its families. An event like this typically gains a lot of attention and gains popularity and momentum over the years. Our Fundraising in a Box will provide you as the first time golf event planner, with a variety of tested tips and strategies to guarantee success for your event.

### *Start Moving! (FIB)*

Who doesn't enjoy getting into shape and raising money for a worthy cause at the same time? Athletic or sports-based events are a great and simple way to raise funds. You could host a 3K or 5K Run/Walk in your community. Golf outings and tournaments have become a very popular way for neighbors to come together, socialize, and raise money. Maybe you could organize a 12-hour dance-a-thon for BDSRA. These events give people a sense of purpose for the activities they do on a regular basis.

### *Letter and E-Letter Writing Campaign (FIB)*

This is one of the easiest and most successful fundraising activities to do. The best letters come from those personally affected by Batten disease--parents, siblings, friends, families, etc. You'll be surprised at how much can be raised by a simple appeal to all those within Sphere of Influence (*see our list of possibilities*).



## More Fundraising Event Ideas

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### *Trivia Night (FIB)*

Trivia nights are informal, fun, competitions where teams battle to see who has the greatest knowledge of trivial matters. General knowledge and trivial interest questions are asked by a trivia host and the winners are the team which, at the end of the night, have correctly answered the most number of questions. Participants form teams of 8-10 and answer 10 questions during 10 rounds of Trivia play. During the fundraiser there is also a silent auction, raffle drawings, and pizza & beverage sales. The night's event is often emceed by a popular local radio disc jockey or television personality.

### *Give a little to get a little*

As a child, did you ever set up a lemonade stand or offer to mow lawns to help make a little extra money on the side? These types of things are very applicable to fundraising in your community. You could organize a neighborhood carwash, garage sale, or even a community bake sale. Why not host a spaghetti dinner with all the trimmings? Providing a service to someone in exchange for their donation lets both sides feel like they've won. Don't forget to mention that you're providing this service to benefit BDSRA. You may be surprised at just how generous people might be.

### *No-Show Events*

This is a great way to raise money with very little effort. How can that be, you may ask? It's very simple—just invite people to a function and ask them NOT to show up! No-show events like potlucks, golf outings, or bingo tournaments encourage people to donate instead of showing up to the event. It's a fun, creative, and easy way to host a great fundraiser. For more examples of a no-show event, please visit the BDSRA website ([www.bdsra.org](http://www.bdsra.org)).

### *The Low-End Event*

This is a unique fundraising idea that turns the usual fancy-schmacy event on its head. Instead of holding a fashionable cocktail party at a high end hotel, hold a hot dogs and beer event at a hotel or in your backyard. Tell your donors that this year is such an important year for your organization, you want to spend most of the money you are raising on your program or mission, instead of the event.

### *Counter Canisters*

Every penny counts! Your change and the change of others adds up to a great deal of money. Place canisters at locations in your local community at gas stations, convenience stores, grocery stores, pizza parlors, etc. to raise money for BDSRA and your child. Share your story on a label and check back frequently to empty the jars and start collecting again. Be certain to place the canisters near the register!

### *Auction*

Ask families, friends and community businesses to donate their specialties, including skills, to be auctioned off. Auction your husbands for "honey-do" projects, etc. Teens for yard work and babysitting. Restaurant and theatre owners can donate dinners and seats to shows. This takes time organizing but can raise a lot of money.

### *Employer Giving—matching gifts, corporate sponsorships and co-worker support*

Unless you are self-employed, the workplace can be a great way to raise funds for a cause. As previously mentioned in this packet, corporations and companies often have programs specifically designated for

charitable contributions. Ask your employer if they have a “matching funds” program or sponsorship opportunities. Spread the word to your co-workers about your upcoming fundraising event and encourage them to attend. Challenge co-workers to a “penny war” to see who can bring in the most spare change to benefit BDSRA. In fundraising it’s important to use the resources available to you, and your workplace can be one of your most valuable resources.

### ***Birthday Donations***

On your birthday, ask your family and friends to make a donation instead of giving a gift. Have a party to celebrate as well as educate others! This is also a perfect Facebook fundraiser, and so easy! You can also do this for someone else's birthday. (You can make up a card saying that a donation was sent to BDSRA in honor of his/her birthday instead of sending a gift.) This is also wonderful at holiday time to do in lieu of gifts.

### ***Basket Party for Batten Disease***

On limited time and need a quick fundraiser? Host a "Basket Party". The family and volunteers ask people to create themed baskets for the event. Participants then have the chance to bid on their favorite basket. Some of the basket themes include a movie basket, teddy bear basket, knitting basket, golf basket, "team" basket, and so many more. The great thing about this fundraiser is that it’s just as much fun putting together a basket as it is bidding on one. Consider having local businesses sponsor or donate items for your baskets.

***Touch a Truck:*** If you like trucks and vehicles you may want to think about this! Arrange for the following to be on display: local fire trucks, ambulances, garbage trucks, postal service trucks, plows, cement trucks....and so many more! Children can get up close and personal with some of their favorite big rigs! Charge an admission!

### ***Salon Benefit for Batten Disease***

Have a long time hairstylist or a well known salon in town? Why not organize a benefit at the salon to raise funds. The salon agrees to provide services (haircuts, manicures, pedicures) at a reduced rate during a block of hours on a busy Saturday. All of the proceeds raised, including tips, go to benefit BDSRA.

## **Sphere of Influence**

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Think that you don't know anyone who can help? Check out the list below of all the people in your network who could be a part of your fundraiser. Your sphere of influence is all the people who you are in contact with on a regular or semi-regular basis. Friends, family, colleagues, business acquaintances, even casual acquaintances (friends of friends for example). This is the most important network for you to tap into because they know you, they support you, they are your foundation, and they know other people who may help your cause.

Family Members  
Close Friends  
Professional Associations  
Colleagues  
Church Members

Doctor/Pharmacist/Therapist/Dentist  
Business Vendors  
Friends of Friends/Kids friends  
Neighbors  
Health Club/Gym



## Budget Planning Worksheet

Use this sample budget sheet to help you plan your event. Feel free to photocopy this page or add and delete things as necessary. Knowing the specifics on your budget is one of the most important aspects to a successful fundraising event.

Event Name: \_\_\_\_\_

Event Date: \_\_\_\_\_

### Projected Income

Ticket Sales/Registration Fees: \$ \_\_\_\_\_

Auction: \$ \_\_\_\_\_

Raffle: \$ \_\_\_\_\_

Sponsorships: \$ \_\_\_\_\_

Advertising sales: \$ \_\_\_\_\_

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

Total Income: \$ \_\_\_\_\_

### Projected Expenses

Venue (Location): \$ \_\_\_\_\_

Equipment rental: \$ \_\_\_\_\_

Catering/Food purchases: \$ \_\_\_\_\_

Printing costs: \$ \_\_\_\_\_

Advertising (flyers, brochures, etc) \$ \_\_\_\_\_

Mailing/Postage: \$ \_\_\_\_\_

Insurance: \$ \_\_\_\_\_

Permits/Licenses: \$ \_\_\_\_\_

Security: \$ \_\_\_\_\_

Entertainment: \$ \_\_\_\_\_

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

Total Expenses: \$ \_\_\_\_\_

**Total Projected Income** \$ \_\_\_\_\_

**Total Projected Expenses** \$ \_\_\_\_\_

**Total Expected Amount Raised** \$ \_\_\_\_\_



## Event Promotion

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There are several ways to gain publicity and promotion of your event. When putting on any event, media coverage is always anticipated and appreciated. What better way to spread the word and advocate for your cause than by a nightly news story or newspaper article? However, many families run into struggles and barriers when trying to gain interest from the media. Here are a few tips to help you gain media coverage for your upcoming fundraiser.

### *Consider all types of communication*

There are so many different types of media coverage out there! You can think small and local, or large and regional. The more interesting or personal your story, the more likely it is that media outlets will want to cover it. Media sources to consider include:

- Newspapers in your city, county, region, or state
- Radio stations both AM and FM (*visit [www.bdsra.org](http://www.bdsra.org) for available PSA*)
- Local TV stations (*visit [www.bdsra.org](http://www.bdsra.org) for available PSA and video footage*)
- Online media including Facebook, MySpace, or your city's website (*see our E-Wareness guide*)
- Trade, professional or business publications
- Evite or handwritten invitations
- Community media, e.g. church newsletters, school newsletters, community calendars, etc.

### *Make your story unique*

Do you know a local hero who can endorse your event or provide a quote? Do you have a great picture of your volunteers or affected children? Does your event have an interesting tie to the community? All of these things can help your story stand out in the media. Cross check the media sources to make sure your event does not clash with another event. Tell your story, make it personal, and invite your friends and neighbors to join you in your cause.

### *Research your media*

Because media outlets receive so many different stories across their desks, it's important to make sure that your story gets to the right person. Research the different media outlets and know the names and addresses of the people who will want to read your story. This can be done by researching online, reading/listening to the media source for information, or calling the media source directly and asking. Don't forget about more personal advertising like a letter to the editor (*see sample*) or radio talk show call-in.

### *Follow-up on your release*

You may want to call the reporter or individual who received your story or press release to see if you can be of any more assistance. You don't want to push the reporter into covering your story, but just offer your assistance and be available.

### *Photograph your event*

Photographs can help make any story more interesting. Take pictures of the actual event including participants, volunteers, games, affected children, and anything else you find unique. Offer the reporter these photos and don't forget to include a caption!

### *Publicize in your workplace*

Does your company produce an employee newsletter or weekly email? If so, see if you can send your event information to the person responsible for passing out this information to help advertise your event. Be sure to put your name and contact information in the details so people can come to you with questions or donations. All of this publicity can help increase your overall attendance and donations.

***Be prepared to accommodate the media***

If you have media persons present at your event, you want to make sure that they have everything they need to do an adequate story. Make sure to supply copies of your news release at your event for reporters to take with them. Encourage your volunteers to speak with media persons and share their personal stories. Ask your reporters to sign in and provide contact information so that you can follow up with them after the event.

***Make it well known that you are raising money for BDSRA***

Be sure to include BDSRA in all publicity related materials. You can provide our mission statement, email address, website, and toll-free phone number to reporters, newspapers, newsletters, etc. Encourage the media to contact BDSRA for any further information on Batten disease or the latest research taking place. We are happy to help promote your fundraiser and provide the media with supporting information.

***Use the template news release on the next few pages to help publicize your event***

The sample news releases allow you to customize the release to your specific event. News releases are great because they are short, sweet, and to the point. It allows a reporter to get a snapshot of your event and decide if this is something they are interested in learning more about and potentially covering.

Fax your press release about a week before your event. You'll also want to send it again the day before your event. The requirements for a radio station, community newsletter, or church bulletin are most likely a little different. Inquire with different media outlets as to their requirements for advertising your event.

***Use BDSRA International Awareness Weekend***

International Awareness Weekend is held the **first weekend of June** as a way to raise funds and awareness for our cause. Using the Awareness Weekend to host an event is a great way to catch people's attention and make them think both locally and globally. You can let the media know that around the world, people are recognizing Batten disease and your fundraiser is just one event contributing to the bigger picture of ending Batten disease. The media will be more likely to cover a story when its origins and links have a wider spread.



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Most of us today have access to and spend a great deal of time using email, Facebook, Twitter, blogging, etc. Use this social media avenue to help raise awareness and spread the word about Batten disease and your event. (for more detailed information on setting up these various accounts, contact [eleslie@bdsra.org](mailto:eleslie@bdsra.org))

**If you have an email account:**

- Add [www.bdsra.org](http://www.bdsra.org) and your own website to your email account signature, giving everyone you email an opportunity to see and view the links.
- Send out emails to your friends, family and co-workers with frequent updates and activities.

**If you have a Facebook account:**

- **Become a fan of Batten Disease Research and Support Association** and encourage your friends to do the same. This is the official homepage of BDSRA on Facebook and fans will receive regular updates from BDSRA on research, families, events, etc. (There are affiliate fan pages for BDSRA that are chapters or unofficial sites--please check to verify you have the international headquarter location)
- **Status Update:** change your status on Facebook frequently so that Batten disease information will stay in the top news feed and on your friends mind more consistently.
  - Ex. Help Adina raise awareness for Batten disease by visiting [www.bdsra.org](http://www.bdsra.org) during Batten Awareness Weekend, June 4-6.
  - Ex. Please help us raise money for Adina's Answer, a fundraising event to raise money for Batten disease research.
- **Create notes and invitations:** If you are a parent/friend/family member of a child affected with Batten disease, write a "note" from your own perspective. Talk about your own childhood dreams and memories and how this diagnosis is affecting you. Then, share how you are excited to be fighting for the dreams and memories of all children affected with Batten disease. Invite people to support BDSRA by visiting [www.bdsra.org](http://www.bdsra.org) to learn more about the disease, upcoming events, how to make donations, host a fundraiser and more.
- **Add BDSRA information to the small text box beneath your profile.** This is an area with great visibility so that whenever someone clicks on your profile, they will see information on BDSRA.
- **Post video links and event invitations to your profile.**
- **Add the Batten Disease Research & Support Association to the "Links" section of your profile under "info".]**

**If you have a twitter account:**

- Tweet about BDSRA updates and events happening in your area. This can be similar to a Facebook status update. Ask friends and family to do the same.

**If you have a blog:**

- **Add a link on your blog to [www.bdsra.org](http://www.bdsra.org).**
- **Make a post about Batten disease and/or your child.** This is very similar to the Facebook note. Post your link to Facebook if you have an account.

**If you are a member of a church, club or other organization:**

- Tell your friends about BDSRA by emailing them, sending a message over a listserve or making a post on a community message board--whether online or in person. Invite fellow members to learn about Batten disease by visiting the web site ([www.bdsra.org](http://www.bdsra.org)) and ask if you can have the link posted on the organization's web site.



## Sample Press Releases and Letters

These sample news releases are designed to help you gain media attention for your upcoming event. These releases are customizable so feel free to add or delete as you see fit. Insert the required details and then send it by fax, email, (*preferred*) or postal mail to your local media outlets (newspapers, radio, television, etc). If you would like them to be on letterhead from BDSRA, please contact our office to provide you with the appropriate information. **Be sure to follow up on your news release to call attention to it and assist the reporter!**

### Press Release for Fundraising Event

For Immediate Release

Contact: Your Name  
Phone Number

#### **(Insert event name) to Benefit Batten Disease Support and Research Association**

Date, City, State - (Insert event name) will take place on (day, date) to rally the community around a worthy cause - raising funds for the fight against Batten disease. The event, which will be held at (place and time), will benefit the Batten Disease Support and Research Association (BDSRA). (Insert a sentence or two highlighting something unique or interesting about your event).

Event organizer (your name) predicts a day of fun and entertainment, including (insert event details). Tickets cost (enter price) in advance and (enter price) the day of the event.

"We've really tried to organize a great event to benefit such a deserving cause," (your name) said. "Everyone is welcome to come and enjoy the fun and at the same time know they are making a positive contribution to help fight Batten disease." (Replace this with your own quote if you have something more personal or relevant to say).

This event is designed to raise funds for Batten Disease research. To sponsor the event, to inquire about details, or to purchase tickets, please contact (your name) at (your phone number) or (your email address).

#### **A Deadly Disease with No Cure**

Batten disease is a genetic neurological disorder that affects children and adolescents. In the United States, one child is diagnosed with the disease every week! Over time, affected children suffer mental impairment, worsening seizures, and progressive loss of sight and motor skills. Eventually, children with Batten disease become blind, bedridden, and unable to communicate. Presently, there is no treatment for Batten disease and the disease is always fatal. By showing your support at the (insert event name), you can help stop this deadly disease.

#### **About the Batten Disease Support and Research Association**

The Batten Disease Support and Research Association (BDSRA) is the largest support and research organization in North America for families that have children with the disease. We currently serve over 1,200 families in the United States, Canada, South America, Australia, New Zealand, and South Africa, just to name a few. Since our inception in 1987, the BDSRA has helped fund numerous scientists in the search for a cure. For more information, please visit [www.bdsra.org](http://www.bdsra.org).

For Immediate Release

Contact: YOUR NAME  
YOUR PHONE

## International Batten Disease Awareness Weekend June 4-6, 2010

June 4, 2010; YOUR TOWN, USA – **Approximately one child each week is diagnosed with Batten disease.** This disease is a particularly rare inherited genetic disorder affecting less than 2200 children worldwide. There is currently no treatment, and no cure. **Most children will die in early childhood never living to see their 3rd birthday party, play little league, attend high school graduation; much less hope of marriage or children.**

The Batten Disease Support and Research Association announces its third annual International Batten Disease Awareness Weekend to be held June 4-6, 2010. Batten Disease Awareness Weekend is recognized all around the world. This day provides BDSRA the opportunity to gather supporters, resources, and voices worldwide to unite for the common goal of increasing awareness and understanding, enhancing fundraising activities, and providing hope to children and families living with Batten disease.

Families and friends of children who have this puzzling and cruel disease will be participating in various activities this upcoming weekend. Some of these activities will include fundraisers, while others will simply be spreading the word about this disease throughout their community. *[Here in “your town” community, the “your name” family will be holding “this” activity.]*

*[Use this paragraph to talk about your fundraiser or awareness day activity. Don't have one planned? Tell people your personal story and let them know how they can contribute to BDSRA.]*

### **A Deadly Disease with No Cure**

Batten disease is a genetic neurological disorder that affects children and adolescents. Over time, affected children suffer mental impairment, worsening seizures, and progressive loss of sight and motor skills. Eventually, children with Batten disease become blind, bedridden, and unable to communicate; eventually followed by certain death.

### **About the Batten Disease Support and Research Association**

The Batten Disease Support and Research Association (BDSRA) is the largest support and research organization in North America for families that have children with the disease. Currently, BDSRA serves over 1,200 families in the United States, Canada, South America, Australia, New Zealand, and South Africa, just to name a few. Since their inception in 1987, the BDSRA has helped fund numerous scientists in the search for a cure. Promising research is being done every day. However, your help is still needed. For more information, please visit [www.bdsra.org](http://www.bdsra.org) or call the BDSRA national office at 800-448-4570. **Please join in this fight to save children's lives.**



**BATTEN  
DISEASE**  
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A LIGHT IN A WORLD OF DARKNESS

**PRESS RELEASE**

**For Immediate Release**

**Contact: Adina Ryan  
Director of Development  
866-287-7233**

The Batten Disease Support & Research Association (BDSRA) is pleased to announce an upcoming [fundraiser, event, opening, etc and provide details of who, what, when, where].

*BDSRA is a 501(c)(3) non-profit organization and mission to be an international support and research networking organization for families of children and young adults with an inherited degenerative disorder known as Batten Disease. All financial contributions go directly to help support families and fund critical research in order to find a cure for this disease.*

**A Deadly Disease with No Cure**

Batten disease is a genetic neurological disorder that affects children and adolescents. Over time, affected children suffer mental impairment, worsening seizures, and progressive loss of sight and motor skills. Eventually, children with Batten Disease become blind, bedridden, and unable to communicate. It does not discriminate against age, race, or socioeconomic status. Presently, there is no effective treatment for the disease and the disease is always fatal.

**About the Batten Disease Support and Research Association**

The Batten Disease Support and Research Association (BDSRA) is the largest support and research organization in North America for families that have children with the disease. Over 90% of our annual budget goes toward program support and research. We have been supporting families since 1987, and our organization continues to gain strength. We encourage you to visit our website at [www.bdsra.org](http://www.bdsra.org) to learn more about the cruelty that is Batten Disease and what you can do to help. You can be the “light in a world of darkness” for a child diagnosed with Batten Disease.



**BATTEN  
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ASSOCIATION  

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A LIGHT IN A WORLD OF DARKNESS

**For Immediate Release**

**Contact:**

**Adina Ryan  
Director of Development  
866-287-7233**

### **Barkin' For Batten Charity Dog Walk raises \$3,200 for Batten disease**

REYNOLDSBURG, OH - More than 25 dogs and their owners weathered rainy conditions to participate in the first central Ohio Barkin' For Batten dog walk to benefit children and families affected with Batten disease, held May 22 at Hannah Park in Gahanna.

More than \$3,200 was collected from participants and sponsors to benefit the Batten Disease Support & Research Association (BDSRA), according to Adina Ryan, Development Director.

*"This dog walk fundraiser was designed not only to raise money for our cause, but to generate interest from new groups in our disease," she said. "Nineteen breeds of dogs are also affected by this rare brain disease, and our hope was to raise awareness to a broader community. We are extremely grateful to all our participants and sponsors in making this first event a success. Their efforts will have a direct impact on moving research forward."*

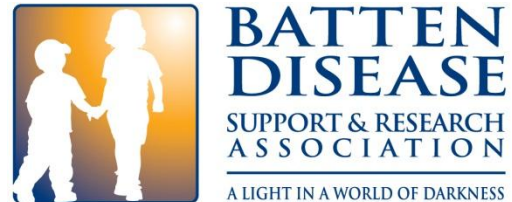
Major sponsors for the event include Pet Butler, Pet Palace, Moochie & Co., Gahanna Animal Hospital and Park your Paws Doggie Daycare.

Batten disease is a genetic neurological disorder that affects children and adolescents. Over time, affected children suffer mental impairment, worsening seizures, and progressive loss of sight and motor skills. Eventually, children with Batten Disease become blind, bedridden, and unable to communicate. It does not discriminate against age, race, or socioeconomic status. Presently, there is no effective treatment for the disease and the disease is always fatal.

The Batten Disease Support and Research Association (BDSRA) is the largest support and research organization in North America for families that have children with the disease. Over 90% of our annual budget goes toward program support and research. We have been supporting families since 1987, and our organization continues to gain strength. We encourage you to visit our website at [www.bdsra.org](http://www.bdsra.org) to learn more about the cruelty that is Batten disease and what you can do to help. You can be the "light in a world of darkness" for a child diagnosed with Batten disease.

## Letter: Potential Sponsors/Business Partners

People and businesses are often happy to give of their goods or services for a worthy cause. Often the hardest part to gaining sponsors is simply getting the courage to ask them. If you publicize their sponsorship and attract media coverage, attracting sponsors can be a piece of cake. Below are a couple sample letters for you to use as a guide. **Feel free to add your own personal details and comments for the best chance of success.**



Date

Contact Name

Business Name

Business Address

Dear (contact name),

I'm writing to ask for your support in making the (event name) a success. I'm organizing this event on (date) to raise money for the Batten Disease Support and Research Association (BDSRA), the leading national non-profit organization for Batten disease research funding, support, patient education, and advocacy. You can help make a difference by supporting this event through a sponsorship or with a donation of (specific request for a donation, goods, or services).

As you may know my (son or daughter), (their name), is currently living with (Batten Disease type). This event is an ideal way for the community to unite and lend their talents to make a difference in the life of (your son or daughter) and children like (him/her).

BDSRA supports over 1,200 families worldwide that have children with Batten Disease. They are a 501(c)(3) organization as identified by the IRS and your donation is tax deductible. With your help, we can make this event a success and raise critical funding for BDSRA, which funds promising research to find a therapeutic treatment and a cure for Batten disease. Please consider making a contribution to this important cause.

For more information about this event and how you can help, please contact me at (your phone) or (your email). For further information about BDSRA, please contact Adina Ryan, Director of Development at 866-287-7233 or visit the BDSRA website [www.bdsra.org](http://www.bdsra.org).

Thank you for your time and consideration. You can be the "light in the world of darkness" for a child diagnosed with Batten disease.

Sincerely,

(Your name)

(contact information)



**BATTEN  
DISEASE**  
SUPPORT & RESEARCH  
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A LIGHT IN A WORLD OF DARKNESS

Date

Contact Name  
Business Name  
Business Address

Dear (contact name),

I am writing to ask that [name of business] consider supporting again this year the event that I am chairing to raise awareness and research funds for Batten disease. As you may recall, Batten disease is a rare brain disease that affects children, including my own [daughter/son] and currently has no treatment or cure.

The [event name] is being held [where] on [date and time]. The event will include [discuss what will be offered--walk, golf, auction, dinner, music, etc.]

This past year has been an exciting year for those of us who know [daughter/son] or any other child affected by this fatal neurological disorder. Remarkable research took place with some exciting results, funded by Batten Disease Research and Support Association (BDSRA). Research revealed in a mouse model that Batten disease is treatable through possible gene therapy and enzyme replacement and has encouraged scientists to continue pursuing a cure in humans as a worthwhile endeavor.

However, there is much more research to be done and we need your help to fund it. Will you please consider supporting BDSRA by becoming a sponsor (partner) of our upcoming fundraiser, [name] to raise money for Batten disease research. There are also promotional benefits for partners depending on the level of donation.

We realize there are a great number of worthwhile causes and I am very much aware of the many requests we all receive for financial support. However, I can promise you that 100% of every donation (less our expenses for the event) will directly fund research--research that will have ramifications for all children living with rare/orphan disorders.

I have attached a one page summary of the event, the cause, and the ways in which you could help. I would greatly appreciate any support you are able to provide. I will follow up with you next week to see if you are willing to become a partner with us in eradicating this disease.

Sincerely

[name.contact info]



**BATTEN  
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A LIGHT IN A WORLD OF DARKNESS

166 Humphries Drive  
Reynoldsburg, OH 43068  
1-800-448-4570  
[www.bdsra.org](http://www.bdsra.org)

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### Sample Letter: Thank you Letter

Showing your appreciation for a donated item or service is vital. Not only does it show that you are thoughtful but it also helps to increase the likelihood that this individual or business will help or donate again in the future. Below you'll find a generic example of a 'thank you' letter. Above you will find a sample BDSRA letterhead. This letterhead graphic is available through the BDSRA National Office. **Personalize it as much as you can for the best impact!**

Date

**The (event name) to benefit the Batten Disease Support and Research Association**

Dear (enter contact name),

Thank you for supporting the Batten Disease Support and Research Association through your donation of \$(enter amount or type of gift given) for the (event name). Your gift is greatly appreciated by BDSRA and the families we serve.

Through donations such as yours, BDSRA is able to continue to fulfill their mission to provide support resources for families who have children with Batten disease. Along with funding vital research, BDSRA works closely with scientists and researchers who are hard at work in hopes of finding a therapeutic treatment and cure for future generations affected by this devastating disease.

You'll be delighted to know that our event was a huge success and raised over (add total amount here) and was attended by (add number of guests), including (anyone notable).

BDSRA is a 501(c)(3) non-profit organization and this donation is tax-exempt under IRS Federal guidelines. Our Federal Tax Identification #91-1397792. Please retain a copy of this letter for tax purposes.

We look forward to the day when we are free of Batten Disease. I would like to take this opportunity to thank you for your valuable support.

Sincerely,

(Your name)

### Sample 3: Letter to participants in event to give out

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Dear Friends and Family,

On [date], I am participating in [event name, location] to benefit the Batten Disease Support & Research Association. This event is [give brief description]. I ask that you support me in this worthwhile cause.

Batten disease affects only 2-4 children annually, including my [friend/daughter/son, grandchild/nephew, etc.] I am participating in this event in honor/memory of (child). Batten disease is a rare, fatal brain disease that cause progressive loss of vision, speech, motor skills, and seizures. Eventually it leaves every child bedridden, unable to feed themselves, and finally leads to early and certain death. There is no treatment or cure.

All proceeds from the [event] will go to BDSRA, a non-profit 501(c)3 corporation and the worlds leading private source of funds fro Batten disease research. Over 90% of every dollar donated to BDSRA directly funds research and family support programs.

Please consider making a donation (which is 100% tax deductible) to support me and these efforts. Online donations can be made at [www.bdsra.org](http://www.bdsra.org). Click on the "Donate Now: button on the top right side of the home page. Please list the event you are supporting in the comments box.

Checks may be made payable to BDSRA and mailed to:  
BDSRA  
166 Humphries Drive  
Reynoldsburg, OH 430568

### Sample 3: Letter to Potential In-Kind Donor

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Dear [name/name of business],

This letter is a request that you consider participating as an in-kind donor in the [event] for Batten Disease Support & Research Association taking place on [date/location/time].

Batten disease is a heartbreaking fatal neurological disease which affects primarily children. Children will experience seizures, gradual loss of sight, speech, motor skills, eventually becoming bedridden and tube fed, and finally leading to early death. BDSRA is the largest private source of funds for Batten disease research in the world. Last year our [event] raised over [amount] for BDSRA! In addition, new research funded by BDSRA has discovered potentially effective treatments in mouse models, which indicates there may be cure on the horizon for these children. Batten disease is currently always fatal. There is no treatment, there is no cure.

You can help by donating goods, gift certificates, or other appropriate items for us to use in our Raffle or Silent Auction. Major donors of goods and services will be recognized as partners in the event.

Please consider this opportunity to contribute to BDSRA and help to find a cure for Batten disease.

Sincerely,

[Name and either event chair, or Batten mom/dad]

## Other Communication

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### Pre-event calendar listing

[Your Town] - The Batten Disease Support & Research Association (BDSRA) walkathon will be held Saturday, May 29 at Blacklick Park. This walkathon will raise much needed money to support Batten disease research.

Registration begins at 10 a.m. with the walk scheduled for 11 a.m. Prizes, games, and entertainment will be featured. Several local athletes are scheduled to sign autographs.

Also on hand will be several area families living with Batten disease, a devastating rare neurological disease affecting primarily children. Batten disease robs these children of their sight, speech, motor skills, and eventually leads to death. Currently there is no treatment, there is no cure. Batten disease is always fatal.

For more information, call Adina Ryan at 866-287-7233 or visit [www.bdsra.org](http://www.bdsra.org).

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### Sample emails to committee members

Hey Guys:

We have our first major sponsor! Joe reports that ABC Company has come on board as our first \$1,000 sponsor. Way to go, Joe! keep those sponsors coming! And thanks to the rest of you who are hard at work recruiting sponsors.

---

Dear Committee Members:

Here's a quick update on what others are doing to raise awareness and money for our upcoming walkathon.

Susan Jones, a teacher at Jordy's school, sent an email around to all of her teacher friends, asking them to join her team or make a donation. "They all know I work with Jordy who has Batten disease and this cause is important to me. I've raised more than \$500 just from that email," she said.

Annie Adams family owns a pizza parlor. She has a picture of her nephew, Ryan, in the parlor along with a jar asking for donations. "The money keeps adding up," said Annie. And some of the regular customers are pledging support for her in the walk.

Whitney and Chris Gherman are taking pledges for the walkathon in honor of their cousin's daughter, Brooke. They are challenging their parents team to see who can raise the most money for the event. The losing team has to treat the winning one to ice cream!

Great work, Susan, Annie, Whitney and Chris! All your great ideas are helping our children. Keep up the good work!

Adina

## Sample In-Kind Donation Form

This form can be used for Silent and Live Auction items, donation of prizes or giveaways, food, etc. Serves as a great resource when organizing an event and can be sent with the request letter to in-kind donors.

### Donation Form

*Thank you for your generous donation of the following item(s) for the upcoming fundraiser to support the Batten Disease Support and Research Association (BDSRA).*

Date \_\_\_\_\_ Estimated Value \$ \_\_\_\_\_ Pick-up Date \_\_\_\_\_

Description of Item \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Donated By \_\_\_\_\_

Address of Donor \_\_\_\_\_

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

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

***\*\* Please contact (insert your name and phone number) to arrange for pick-up of the donated item. All items will be needed by (insert date).***

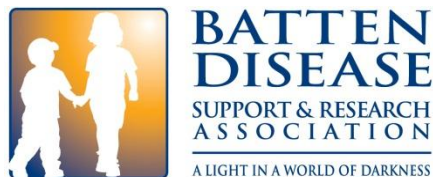
BDSRA is a 501(c)(3) charitable organization and all donations are tax-exempt (Federal Tax Exempt #: 91-1397792.) All proceeds will benefit BDSRA's support and research efforts.

For more information about BDSRA, please visit their website at [www.bdsra.org](http://www.bdsra.org)

***\*\*Please retain a copy of this form for your tax purposes.\*\****

## Sample Ticket Receipt Form

This form can be used for Ticket sales for events and serves as a tax-receipt for donors. Please be sure to calculate the amount of "value" for food, drink, gifts that they will receive in exchange for their ticket. Typically, it's the ticket price minus food costs.



### Ticket Receipt

*Thank you for your ticket purchase for the upcoming fundraiser to support the Batten Disease Support and Research Association (BDSRA).*

### Event Details

Date of Event: \_\_\_\_\_ Time of Event: \_\_\_\_\_  
Name of Event: \_\_\_\_\_  
Hosted By: \_\_\_\_\_  
Location: \_\_\_\_\_

### Attendee Confirmation

Name(s): \_\_\_\_\_  
Address: \_\_\_\_\_  
City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_  
Phone: \_\_\_\_\_ Fax: \_\_\_\_\_ Email: \_\_\_\_\_

Ticket Price \$ \_\_\_\_\_ @ Quantity: \_\_\_\_\_ = Total Cost: \$ \_\_\_\_\_  
(-Value of Good and Services Received): \_\_\_\_\_  
Tax-deductible Amount: \$ \_\_\_\_\_

BDSRA is a 501(c)(3) charitable organization (Federal Tax Exempt #: 91-1397792.) All proceeds will benefit BDSRA's support and research efforts.

***\*\*Please retain a copy of this form for your tax purposes.\*\****

## You're on your way!

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Now that we've given you the tools you need to succeed, it's up to you to do the rest. The Batten Disease Support and Research Association will be here to help you every step of the way, should you need it. Remember, **THE CURE DEPENDS ON US!** Together we can all raise money and help make a difference in the lives of our children.

Below is a list of additional resources that you can use in your fundraising quest. Please know that any of the graphics within this document are available to you. Please contact the BDSRA National Office for a copy. With the numerous advances in Batten disease treatment recently, it truly is an exciting time to be raising money for research. Good luck on your future event!

BDSRA Development Department  
Adina Ryan, Director of Development  
Eric Leslie, Media/PR Coordinator  
866-287-7233  
aryan@bdsra.org  
eleslie@aol.com

### **The Practical Guide to Raising Serious Money**

Author: David Lansdowne  
Available on Amazon.com

### **Do-It-Yourself Fundraising Ideas**

Fun and unique ideas for your next event  
[www.fundraising-ideas.org](http://www.fundraising-ideas.org)

### **Network for Good**

Fundraising 101 Guide  
[www.fundraising123.org/fundraising](http://www.fundraising123.org/fundraising)

### **Grassroots Fundraising Journal**

Free newsletter & articles about fundraising  
[www.grassrootsfundraising.org](http://www.grassrootsfundraising.org)

### **Philanthropy Journal**

Helpful website on state (NC), national and international news on fundraising  
[www.philanthropyjournal.org](http://www.philanthropyjournal.org)

### **USA Fundraising**

Many helpful tips and ideas for your next fundraiser or event  
[www.usafundraising.com](http://www.usafundraising.com)

### **1001 Fundraising Ideas & Strategies**

Author: Jim Hawkins  
The title says it all! Available on Amazon.com