PATIENT INFORMATION
Our expert Medical Board will answer your questions and provide information on any issue. Call or write to Debbie Judy - she is standing by ready to help you!

PATIENT CLINICAL TRIALS
We give you an updated list featuring doctor’s name, phone number and explanation of treatment protocols.

PATIENT TRAVEL FUND
Families traveling to clinical trials can receive up to $500 for travel expenses. Contact our office to receive an application form.

GLOBAL NETWORK OF VOLUNTEERS
You are not alone — patients and families will share their treatment experiences with you. Call us to make a friend!

PATIENT REGISTRY
Statistics on these diseases seem to be as rare as the diseases themselves. Please fill out our Patient Registry Form for surviving or deceased patients. The more data we collect, the more data we can use for research.

YOU CAN HELP
Please donate your blood & platelets, have your bone marrow tested, and financially donate to the AA&MDSIF’s research & support efforts. We are proud to spend only 6% on administrative and 2% on fundraising costs. Please compare our performance with other charities when making your tax-deductible contributions.

ANNOUNCING NEW ADDITIONS TO OUR WEBSITE!

The AA&MDSIF Conference Webinar Features Discussion by Leading Experts in Bone Marrow Failure Disease

The first webcast of the 2004 Aplastic Anemia & MDS International Foundation’s Patient and Family Conference highlights basic discussions of AA, MDS and PNH. You are able to watch presentations by Dr. Mikkael Sekeres of the Cleveland Clinic Foundation in Cleveland, OH and Dr. David Araten of Memorial Sloan-Kettering Cancer Center in New York, NY to gain a better understanding of bone marrow failure diseases and treatment options. You are able to see and hear the doctors’ presentations as well as their Power Point slides. The webcast archive is viewable at [www.aplastic.org/webinar](http://www.aplastic.org/webinar).

The 2004 AA&MDSIF Patient and Family Conference provided a forum in which nearly 300 patients and caregivers directed questions about their particular bone marrow failure diseases to leading doctors in the fields of hematology and bone marrow disease. The doctors answered questions and provided critical information on ways in which to manage and treat bone marrow failure diseases.

For more information regarding the 2004 AA&MDSIF Patient and Family Conference, visit the Foundation’s website at [www.aamds.org](http://www.aamds.org) for a downloadable version of the speaker abstracts from the conference program guide.

Drug Information Page Coming Soon

The AA&MDSIF Drug Information page is being developed to provide patients with general information about medicines used to treat aplastic anemia, myelodysplastic syndromes (MDS), and paroxysmal nocturnal hemoglobinuria (PNH). This page will be available on our website at [www.aamds.org](http://www.aamds.org) and will include information about drugs that are considered standard therapy for these diseases as well as many drugs that are in clinical trials.
RECENT MEDICAL LITERATURE

You can search the medical literature for updated research by going to the National Library of Medicine bibliographic database, MEDLINE, at www.pubmed.gov. MEDLINE lists journal articles along with author summaries of these articles. Below you find just a few new items recently indexed in MEDLINE. Contact Debbie Judy at info@aamds.org if you have any questions about doing your own MEDLINE search. Contact your hospital librarian to obtain a copy of the full article or to search other medical databases.

APLASTIC ANEMIA


MDS


PNH


ALSO NEEDED

VOLUNTEERS WHO HAVE TAKEN VIDAZA

If you have taken Vidaza and are willing to speak with other patients to share your experiences, please contact AA&MDSIF at 800-747-2820 or visit www.aamds.org to join the Global Volunteer Network.

ONLINE VIDEO PRESENTATION ABOUT HOW VIDAZA WORKS

This online video presentation, produced by Pharmion, is viewable at: www.vidaza.com. It includes an overview of MDS, Vidaza mechanisms of action and overview of clinical trials results. Patients can contact the Vidaza Hotline at 1-866-742-7646 to find out about Vidaza reimbursement and general information about the medicine.

ALEXION REACHES AGREEMENT WITH FDA FOR PHASE III STUDY OF ECULIZUMAB

Alexion Pharmaceuticals, Inc. announced recently that it has received written confirmation from the U.S. Food and Drug Administration (FDA) indicating agreement with the two protocols constituting the pivotal Phase III program of its investigational drug eculizumab for paroxysmal nocturnal hemoglobinuria (PNH). The Phase III program included the TRIUMPH pivotal trial together with a companion safety trial called SHEPHERD. The agreement for the Phase III program was reached under the FDA’s Special Protocol Assessment (SPA) process, a procedure by which the FDA provides official evaluation and guidance on proposed protocols for pivotal Phase III clinical trials. It is expected that, if successful, the trials will complete the filing package that will serve as the primary basis of review for the approval of a Biologics License Application for the PNH indication. Find out more by visiting Alexion’s website at www.alexion.com. Also, review recent articles posted on BioWorld Online at www.bioworld.com.
### 2004 Holiday Card Order Form

**FOUR SEASONS:** Four softly shaded panels each feature an embossed silver foil tree depicting each season of the year. **Front reads:** “Seasons Greetings” **Inside verse:** “May the peace and joy of the holiday season be with you throughout the coming year.” Silver foil lined envelope. Size: 8” x 5 1/2”

**SNOW PEOPLE FAMILY:** Cute snowman family prepare for the holidays. **Front reads:** “The Spirit of Christmas is Love.” **Inside verse:** “Wishing you a beautiful holiday season and a New Year of peace and happiness.” Envelope has cutout for baby snowman to show through when inserted. Size: 8” x 5 1/2”

**REJOICE:** Rich cream, navy blue and gold foil adorn this card front, which shows three wise men bearing gifts (embossed gold foil), on a bed of holly & berries. **Front reads:** “Rejoice in the Lord.” **Inside verse:** “May his love be in your heart this Christmas and all through the coming year.” Navy deckled edge envelope. Size: 8” x 5 1/2”

**MERRY CHRISTMAS:** Beautifully rich and elegant in shades of sponged gold with gold foil accents. Center insert has shades of green sponging with “Merry Christmas.” **Inside verse:** “Warm Wishes for the Holidays and for a Happy and Healthy New Year.” Gold foil lined envelope. Size: 8” x 5 3/4”

**PATRIOTIC SNOWMAN:** Snowman dressed to show his patriotism, holds a silver foil banner that reads, “Seasons Greetings”. **Inside verse:** “Wishing you and all those close to you a joyous holiday season and a New Year of happiness and hope for a world at peace”. Silver foil lined envelope. Size: 5 3/4” x 8”

**HOLLY JOLLY REINDEER:** Whimsical reindeer dressed for the holidays and ready to decorate. **Inside verse:** “Best Wishes for a happy holiday season and a happy New Year.” Gold foil lined envelope. Size: 5 3/4” x 8”

**PEACE:** The word “Peace” embossed in gold foil stands out among streaks of gold, red and green. **Inside verse:** “As we pause to celebrate this Birthday of our Lord, we also celebrate the love that brings us all together. May your Christmas be filled with celebration and your New Year blessed with peace.” Gold foil lined envelope. Size: 5 3/4” x 8”

**STAR BRIGHT:** A bright contemporary blue foil star highlighted with blue and silver foil designs. **Front reads:** “Happy Holidays.” **Inside verse:** “May the joys of the season be with you throughout the coming year.” Silver foil lined envelope. Size: 5 3/4” x 8”

All cards carry this message on inside cover (not on verse side): “A contribution has been made to the Aplastic Anemia & MDS International Foundation to fight aplastic anemia and myelodysplastic syndromes.”

---

**Return lower section with your check to:** Gail Walker 4769 Goodison Place Drive Rochester, MI 48306

Make check payable to: AAFM

Please allow 2 weeks for delivery.

<table>
<thead>
<tr>
<th>DESCRIPTION</th>
<th>QUANTITY</th>
<th>PRICE</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Four Seasons</td>
<td></td>
<td>23.50</td>
<td></td>
</tr>
<tr>
<td>Snow People Family</td>
<td></td>
<td>23.50</td>
<td></td>
</tr>
<tr>
<td>Rejoice</td>
<td></td>
<td>23.50</td>
<td></td>
</tr>
<tr>
<td>Merry Christmas</td>
<td></td>
<td>23.50</td>
<td></td>
</tr>
<tr>
<td>Patriotic Snowman</td>
<td></td>
<td>23.50</td>
<td></td>
</tr>
<tr>
<td>Holly Jolly Reindeer</td>
<td></td>
<td>23.50</td>
<td></td>
</tr>
<tr>
<td>Peace</td>
<td></td>
<td>23.50</td>
<td></td>
</tr>
<tr>
<td>Star Bright</td>
<td></td>
<td>23.50</td>
<td></td>
</tr>
<tr>
<td><strong>SUBTOTAL</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Please accept my additional donation of...

**TOTAL OF CHECK**

---

QUESTIONS? CALL (248) 651-0091 or (248) 624-1394
ATTENTION MEDICAL RESEARCHERS... The AA&MDSIF is accepting applications for various types of Researcher Awards. We are interested in funding medical research studies relating to the prevention and treatment of bone marrow failure diseases. Application forms may be obtained by calling our office or can be downloaded from our website: www.aamds.org.

THE SIXTH ANNUAL YAHN FAMILY BBQ HELPS FUND MEDICAL RESEARCH... Thanks to Joann and Don Yahn, who worked year-round to organize their sixth annual chicken barbecue and benefit auction in honor of their daughter Torry Yahn, Brianna Johnson and Ashlee Tellie, three young girls who lost their fight against Aplastic anemia, over $20,000 will go towards funding medical research of bone marrow diseases.

COMBINED FEDERAL CAMPAIGN... Please encourage your co-workers to donate to the AA&MDSIF - Agency 0816 - through your federal place of employment. Remind them of our low administrative costs and ask them to compare our efficiency and services with other charities. Every dollar helps!

CONFERENCE AUDIO TAPES... To receive your FREE conference tape, call us or e-mail your name and address to bradley@aamds.org. Whether or not you attended this conference, the latest information about standard and investigational treatments for AA, MDS and PNH is worth hearing.

CHILDREN’S BROCHURE AVAILABLE... "Talking to a Child About Bone Marrow Disease" was created to help adults discuss the various difficult issues of illness and treatment. Contact the AA&MDSIF office to receive your free copy. A great tool for parents, family members and health care professionals.
Your generous gifts help us to: *fund medical research to find a cure*; *provide patient support and advocacy*; *distribute educational materials and updated medical information*.

**Print Your Name:** _______________________________

**Address:** _____________________________________

**City:** _________________________________________

**State:** ________________________________________

**Zip:** _________________________________________

**Daytime Phone:** (               ) _____________________

**email address:** _________________________________

Enclosed is my tax-deductible gift of:

($35) ____ ($50) ____ ($100) ____ ($500) ____ Other ____

**PAYMENT OPTIONS:**

♦ Make your check, money order or traveler’s check payable to:  
  Aplastic Anemia & MDS International Foundation, Inc.

♦ BY CREDIT CARD: □ VISA □ MASTERCARD
  □ AMERICAN EXPRESS

**ACCOUNT #: ______________________________________

**EXP. DATE: ______________________________________

**SIGNATURE: ______________________________________

All donations received by December 31st will be acknowledged in our Annual Report and End-Of-Year Thanks published in our Winter Newsletter for annual donations over $500.

---

In Honor of....If you wish to make your gift in honor of a loved one, print the necessary information in the space below. An acknowledgment of your gift will be sent out to whomever you specify.

**This gift is made in honor of: (Please Print Clearly)**

____________________________________________

**Please notify:**

**Name:** _______________________________________

**Address:** _____________________________________

**City:** _________________________________________

**State:** ________________________________________

**Zip:** _________________________________________

¤ I have enclosed my company’s Matching Gift Form to increase my giving to the AA&MDSIF.

¤ Please contact me with further information concerning ways of giving by will, trust, life insurance, gifts of stock, real estate or other special opportunities.

*The AA&MDSIF is solely supported through individual contributions and is a non-profit charitable organization as described under the Internal Revenue Code, Section 501(C)(3).*

For more information, please call the AA&MDSIF at:

800.747.2820 or 410.867.0242

or help@aamds.org

---

**Know Where Your Money Is Going...**

The American Institute of Philanthropy has determined that the reasonable industry standard for administrative and fundraising expenses is a maximum of 40%. The AA&MDSIF is proud to spend only **8%**. Please compare our performance with other organizations when making your annual charitable contribution.

![Pie chart showing 6% Administrative Expenses and 92% Patient Support & Research]