



MESSAGE FROM THE EXECUTIVE DIRECT

Dear Friend of MGA:

Little did we know that as we mailed our spring 2020 Keystone of Hope newsletter in February that in only a few short weeks, our world would be changed forever. We have all felt the significant impact the COVID-19 pandemic has had on our region, our state and our country.

Although we are all still dealing with these impacts on a daily basis, I am pleased to report that MGA has remained steadfast to our mission to provide medical, social and emotional support to patients with Myasthenia Gravis.

As the size and scope of the pandemic became more evident, the MGA team acted quickly to formulate a plan of action that would allow us to still provide care and support to our patients through the use of telephonic and video technology. Words cannot express how proud I am of our team for how they met this challenge head on and worked through any issue that was presented to them.

As you read this issue of the Keystone of Hope newsletter, you will see many new innovations that we implemented or are planning to implement in order to provide high quality care and support to our patients in the safest way possible. Concepts

like video visits are now available for patients to take part in and virtual support groups are being considered and formulated. An on-line auction and our Butterfly Tribute Tree have allowed patrons of MGA to continue that support from a distance. Long held traditions like the Annual Meeting and Educational Conference will be continued in a virtual setting to allow for continued learning while also social distancing for safety.

Yes, how we are providing care and support to our patients has changed, but what hasn't changed is our commitment to support the mission and vision that has defined this health care organization for the last 65 years.

I hope you enjoy this issue of the Keystone of Hope newsletter and I look forward to the opportunities that the coming months will bring for us to connect and collaborate.

Thank you for your continued partnership.

Jim Joyce, Executive Director MGA of WPA

MG Association News Page 1

MARK YOUR CALENDAR: WE MGA 64th Annual (Virtual) Meeting

With all of the social distancing requirements associated with the COVID-19 pandemic, the MGA Team and Board of Directors have decided to make this year's annual meeting a virtual meeting. The 64th Annual Meeting and Educational Seminar will take place on Saturday, November 7, 2020 from 12 pm – 1:30 pm. Although having the event virtually will be a new endeavor for our organization, we think it will still provide attendees with an excellent opportunity to interact with other patients, staff members and the MGA Board of Directors. Attendees will hear guest speakers and have a chance to ask questions to the MGA medical team. There will also be door prize drawings for those who attend this event. RSVP's are required to join. Please contact Donna to RSVP at 412-566-1545 or donnak@mgawpa.org and you will be sent a link you can use to access the virtual meeting on November 7, 2020.



WELCOME NEW MGA BOARD MEMBERS

REITA DERRICK has been a Liaison with VITAS Healthcare for almost three years. In this capacity, she has intimate, guiding conversations with individuals with life-limiting illnesses and their families. Previously she had worked with senior communities in several capacities including Home Instead Senior Care and Brookdale Senior Living. Reita is married with four children and lives in Jefferson Hills. Her hobbies include hiking, biking, knitting and a steady stream of home refinishing projects with her family. She is very happy to work with MGA and looks forward to ensuring there is broader messaging and understanding about myasthenia gravis.

PHYLLIS MROSCO has worked in all phases of Long Term Care working with the elderly for the past 25 years. Prior to that, Phyllis was an accountant in the shopping center industry. Phyllis has a BS in accounting and business management from Carlow College. She retired from Excela Health as a Physician Liaison where she worked directly with physicians, specialists and staff. Phyllis is eager to assist MGA with her knowledge of marketing and development.

Winter Car Care - \$10 OIL CHANGES for MGA FRIENDS and SUPPORTERS

With winter fast approaching, it is important to make sure your car is ready for the cold weather. Failure to perform regularly scheduled preventative car maintenance can cause breakdowns and make your vehicle unsafe.



The Myasthenia Gravis Association of Western PA is proud to partner with Midas to offer free and discounted oil changes. For each \$10 donation to MGA (a 50% discount), you will receive a coupon card good for a) a free oil change (or \$20 off any service) and b) a \$12.99 oil change (or \$15 off any service). Oil changes include up to 6 quarts of Conventional 5w20-30 motor oil, an in-stock filter, a tire rotation and a visual brake inspection.

The coupon cards are good at over 100 participating Midas shops located

throughout Pennsylvania, Ohio, New York, Michigan, Kentucky and Georgia. Visit www.midaspromos.com for a complete list of participating locations.

Remember, you will receive a coupon card for every \$10 donation you make to MGA and the cards do not expire until April 30, 2021, so make multiple \$10 donations and cover your oil changes throughout the winter and into the spring.

For more information, call the MGA at 412-566-1545. To purchase the Midas Coupon Cards, make checks payable to MGA and mail to MGA of WPA, 490 East North Avenue, Suite 410, Pittsburgh, PA 15212. Please include "Midas Card" in the memo line of your check.

HOW TO **Set Up for Video Visits for MGA**



By Cindy Spring, RN

Due to the COVID-19 pandemic, the MG Treatment Center is not seeing patients in the office at this time. Following the steps below will help you get ready to do a VIDEO visit through the MyChart app. You will need access to an iPhone or Android Phone to begin. Have your WiFi turned on and all other apps closed.

- Type MyChart in the search box in your IPhone app store or the Android PlayStore. The MyChart app is red with a white or clear heart inside. Download
- Next click on Pennsylvania and then AHN or Allegheny Health Network to get the correct MyChart.
- You may need an Activation Code. If you need this, call either, MyChart Support @ 1-833-246-2478, OR Cindy @ 412-566-1545, OR Savannah @ 412-359-6683.
- Next set up your User Name and Password. Be sure to write them down so that you don't forget what they are.
- After you log in, you will come to a screen with several icons, one of which is Appointments. Click Appointments.
- On the next screen you will find another icon eCheck-in. Click this icon.
- Complete eCheck-in by reviewing the information in each step and tapping the This Information Is Correct button at the end of each question or section. It will let you know when you have completed your eCheck-in by saying ready for visit.
- When eCheck-in is complete, the green video icon will appear on the appointment at the appointment icon.
- On the day of your appointment, simply log into MyChart ten to fifteen minutes prior to your appointment time. Click on Begin Visit. This will send a message to the doctor that you are present in the virtual waiting room. He will be with you shortly. *Have WiFi on and all other apps closed. *Have phone connected to charger.

Thank you for your patience, and we hope that you and your family are staying safe and wearing your masks during this pandemic. For questions call 412-566-1545.

ON-LINE SPORTS Memorabilia

Thanks to everyone for making our 1st On-Line Sports Memorabilia Auction a GREAT success!

Many thanks to the sponsors of our auction items...

PA State Representative Anita Kulik

www.pahouse.com/kulik/

NuFACTOR - a Specialty Infusion Company www.nufactor.com

Seniors Blue Book www.seniorsbluebook.com

Bill and Alice Murtha in loving memory of Carole K. Murtha

The Joyce Family in memory of James J. Joyce Sr. and in honor of Robert Collet, Juanita Collet, Irene Joyce and Drew McCoy

> Wendy and Mike McIntyre **Phyllis Mrosco Al Parris**



MICROSOFT REWARDS/ **Give** with Bing

A New Way to Support the MGA of WPA

Microsoft Rewards/Give with Bing is a free program that rewards users for doing the things they already do every day. Participants can earn points by searching, shopping, and gaming with Microsoft and redeem those points to support not-for-profit organizations like MGA.

Simply search for "Microsoft Rewards" and follow the directions to register for the program. Once you are a registered user, go to the "Give with Bing" section, turn on your give mode and select the Myasthenia Gravis Association of Western Pennsylvania, Inc. as the organization you would like to support. If you have any trouble in registering for the program, please contact the MGA office at mgaoffice@mgawpa.org.

Each time you use Bing as your internet search engine, a donation will be made to MGA. There are also other opportunities to give by participating in daily surveys, quizzes, etc.

It's easy, it's free and it will help support MGA all year long! Please share this information with your family, friends and co-workers and ask them to participate as well!

FALL • 2020 Page 3

BUTTERFLY







"We delight in the beauty of the butterfly, but rarely admit the changes it has gone through to achieve that beauty." ~ Maya Angelou

In the 65 years that the Myasthenia Gravis Association of Western PA has provided services and support to patients with Myasthenia Gravis, many traditions have been created and celebrated. In honor of that 65 year milestone, we created opportunity for friends of our program to recognize and honor their loved ones that we hope will become a tradition to be celebrated for many years to come.

As a part of our Butterflies of Hope program, the Butterfly Tribute Tree has been established. The Butterfly Tribute Tree provides individuals and families with a meaningful way to honor or memorialize a loved one or friend with whom they have shared special memories with over the years.

During the summer, a butterfly shaped ornament was mailed to past donors and supporters of MGA. They were invited to decorate the ornament as they wished - potentially including their loved one's name, some special words or something meaningful in the decoration and maybe a small photo. All returned ornaments were then placed on the Butterfly Tree mural which was created by MGA Board Member Reita Derrick.

The Butterfly Tribute Tree will be displayed at the MGA office between now and June 2021. Our hope is that patients, families and other visitors to the office will be inspired by the tree and what it represents.

If you are interested in receiving a butterfly ornament to decorate for the Butterfly Tribute Tree, please contact Donna Kalisek at (412) 566 - 1545 or donnak@mgawpa.org.

THANK YOU to the following who have donated to the "BUTTERFLY TRIBUTE TR

Raymond Beeson

Elizabeth Blume

Dee Carmichael

Jill & David Carr

Bob & Juanita Collet

Carol Cooper

Peggy Critchlow

Deborah Davis

Beverly Dehring

Kathy Dick

Russell Duffy Jr.

Gerri Felice

Fred & Kathryn Guenther

Cheryl Hendricks

Jim & Robin Joyce

Sheryl Kalick

Donna Kalisek

Tammy Kohan

William LaFranchi

Robert & Madeleine Madrishin

Sheryl A. Maletic

Michael McIntyre

Mel & Marlene McRoberts

Kirsten Meister

Pauline Napolitano

Donald & Barbara Neal

Bonnie Repasky

Mr. & Mrs. Joe Revay

Randy Shellhammer

John Shields

Robert Simon

Robert Sippos

Yvonne L. Smith

JoAnn Somma

Swen E. Swenson III

Natalie & Ernie Tack

Geraldine Tyson

Susan L. Ulmer-Breeger

Michael & Paula Wasick

Gretchen Wessel

Gary & Hope Wojtasiak

Vivian Zuccher

Dr. Blume TRIBUTE

By Donna Kalisek

Robert P Blume MD, passed away on April 8, 2020 at the age of 93. He was a

devoted neurologist with the MG Association and a good friend. He leaves behind his loving wife Elizabeth, three children, many grandchildren and great-grandchildren. Dr. Blume enjoyed a very full life, he was educated in Greek and Latin, served in the Army and as a

naval reserve officer on merchant ships, had a deep religious faith, and many other interests. He graduated from Temple University in 1956 and did an internship at Mercy Hospital where he decided to specialize in neurology. He then returned to Philadelphia for a three-year residency at University of Pennsylvania where his interest in myasthenia gravis took hold. His residency was interrupted by a stint as an Army doctor with the rank of Captain at Fort Hood. After returning to Pittsburgh in 1964 Dr. Blume was

appointed Director of the MG Treatment Center at Mercy Hospital where he served until his retirement in 1993. He cared for his many patients for thirty years and continued his relationship with many long after his retirement. He had a particular bond with those he treated and with the staff at MGA. (This is a synopsis of his many accomplishments due to space

constraints)

I met Dr. Blume in 1968 when I was diagnosed with myasthenia at the tender age of nine. His friendly demeanor and compassion were so palpable to a scared little kid, his reassurances to my parents during that time was so crucial and very

much treasured. But that was Dr. Blume... easy going, thoughtful, knowledgeable, concerned. During those early years in the 1970's I was in and out of the hospital/ICU a lot but he was always there with that supportive "We'll get you through this" or a simple pat on the shoulder or hand. Dr. Blume's caring ways touched so many patients both young and old, as well as family members. MG is such an unpredictable chronic illness that it can manifest in so many ways that each person needed to be managed in a

different way. I could go on and on with stories of his dedication to me and others but space won't allow. After his retirement, a small group of us would get together to celebrate his July birthday and make sure he knew how much he was respected and cared for. I grew to love him very much, he became more than just my doctor, he was someone I looked up to, someone I admired, someone I'll never forget. My heartfelt condolences to his family and all those who knew him.



By Sharon McFadden Gaines

Dr. Blume was my doctor, my friend and my mentor. I met him when I was 12 years old. At that time, I was a scared child with a disease I did not understand. Growing up in a hospital was a challenge but Dr. Blume was always kind and compassionate. He always gave me hope during those days. In addition to hope he gave me my life. Dr. Blume was knowledgeable, kind and had empathy for all of his patients. I looked up to him and strive to emulate the qualities that made him the person we all knew. I am blessed to have had him touch my life and forever grateful. My deepest sympathy goes to his family and friends.



Due to the Covid-19 pandemic the May 2020 Highmark Walk was held virtually. We missed seeing the many MG walkers at the new Heinz Field location this year along with all the fun filled festivities. Thank you to everyone who supported MGA again this year and we hope that 2021 will bring a more spectacular event. In conjunction with the Highmark Walk, MGA also had a 50/50 Raffle which many of you that came to the Treatment Center participated in. The drawing was held on May 9th (actual day of the Walk) and **the lucky winner was Debbie Eloi!** We want to thank the Eloi's for very generously donating their winnings back to our organization. Remember that all monies raised for MGA through the Highmark Walk go directly to patient services. Thank you for your continued support and we hope that everyone is staying safe. See you all next year at the **2021 HIGHMARK WALK FOR A HEALTHY COMMUNITY**.

FALL • 2020 Page **5**

Thank you to all of our generous donors!

The following donations were received between January 1, 2020 and June 30, 2020.

Jonathan & Moreen Acker Allegheny Health Network

Amazon Smile **Anonymous**

Edward & Lynn Baltes

Jo Beth Barr

Johanna Baurnes

Katherine Baurnes

Lorne & Maret Beal

Amanda Behe

Greg Behe

Benevity Giving Platform

Ed & Julianne Biehl

John & Norene Block

Bob O'Connor Golf Course

Linda Brown

Casper Caceci

Carnegie Museums

Christian W. Klay Winery

James H. Christy

Clark Hill, PLC

Mel & Kim Cook

James & Kathleen Cordner

Tony & Rose Corrado

Matthew Cusick

Mark Daday

Sylvia & Bob Danehy

Deborah Davis

Loretta Dawkin

Jan W. DeBlasio

Reita Derrick

Robert Downs & Family

Gerald Dudas

Jerry & Margery Dudash

Tami Dulick

James M. Edwards

Facebook/Anonymous

Virginia Farnsworth

Gerri Felice

Theresa Findle

Jeff & Terri Fink

Margaret Jameson Forbes

Jean Frye

Margaret Gabriel

Danielle Gangone

Gateway Clipper Fleet

David Gaudio

Michele Gaynord

Glam Earth, LLC

Michael W. Glass

Glengarry Golf Links

M/M Tom Golden

Roy & Janet Graham

Robert & Amy Grogan

James & Rhonda Gross

Kathryn & Fred Guenther Michael & Judith Hannon

Stephen Herbold

William Hetrick

Highmark BC/BS

Alan & Betsy Hohlfelder

David W. Hollenbaugh, Jr.

Bob & Anne Hornick

Norma Jean Johnson

Janelle Smith Jones

Jim Joyce

Michael Kail

Tracey Kail

Sheryl Kalick

Donna Kalisek

Tracy Kalup

Merrie Kantz

Elizabeth Klimchock

Kline, Keppel & Koryak PC

David & Barbara Klingensmith

Dwight & Nancy Korber

Fred & Susan Krawchick

William & Nancy Kukurin

Joseph Kulik

Ken & Jane Kwasniewski

Robert & Kathleen Lee

Jason & Julie Lerro

Charles & Cheryl Lingenfelter

Lisa Lohman

Theresa Lukaesko

Robert & Nancy MacLachlan

Robert Madrishin

Robert Malcolm

Sheryl Maletic

Richard Mandera

Donald E. Marteeny

Nicholas & Linda Matteo

Edwin "Bud" Maus

Brandi McClure

Mike & Wendy McIntyre

Noemik McIntyre

Laurie McKiernan

Meadowcroft Museum

& Rockshelter

Walter & Martha Meyer

Richard H. Miller

Margaret Mingione

Leslie Molinaro

Lisa Moretti

J. William Murtha

Sally Muzzie

Pauline Napolitano

Donald & Barbara Neal

Diane Nicoletta

Valerie Thomas Njie

Consuelo Nojeim

Mary Linda Panasko

Alva Parris

Nancy Patton

Alan & Nancy Pearson

Rose Peluso

PA Trolley Museum

Maureen Perkey

Virginia Peters

Laurie Phillips

Robert Podurgiel

Eugene & Kathryn Polliard

Thomas & Marcia Pratt

Joseph & Mary Puppo

M/M Thomas F. Quinn

Anthony & Nancie Ranalli

Bonnie Repasky

William & Mary Robeson

Beth Roedler

Elizabeth Roskovich

Donald & Geraldine Rowe

Andrew & Margery Rubin

Donna Ruscitto

Kate Ryan

Noel D. Sallie

Marc & Beverly Santicola

Matt & Michelle Sayenga

Emily Saylor-Richter

Judy Schiffbauer

Cindy Schoeber

Greg Schonotzer

Ron & Carolyn Schott

Louis & Judy Schrecker

Randy Shellhammer

John Shields

Magda Sidhom

Robert Simon

Edward & Amy Skiba

Marianne Skiba

Keith Smetak

David C. Smith

Tim & Melinda Smith

JoAnn Somma

Wallace Specter

Nicole Stachura

Faith Ann Stipanovich

Swen E. Swenson **Deborah Taylarides**

Deborah Theriault

Sarah Carr

Tammy Viehdorfer

Monica Vitkay Barbara Volpe

Keith Waltower

Washington Wildthings

M/M Maurice Weinschenker

John Weyandt

Gene Yatchyshyn Peter & Alicia Zavitsanos

KEYSTONE

Keystone of Hope is published twice a year by the Myasthenia Gravis Association of Western PA, and direct mailed to patients, donors and friends. It is also available at www.mgawpa.org.

Editor: Jim Joyce, MGA, Executive Director Editorial Assistant: Donna Kalisek, MGA Administrative Coordinator Contributor: Cindy Spring, RN, CCM, MGA Patient Support Coordinator

Designer: PilarDesigns **Printing:** Courtesy of Highmark Print Shop

MGA, 490 East North Avenue, Suite 410, Pittsburgh, PA 15212 (412) 566-1545 • www.mgawpa.org

Honorariums & Memorials from January 1, 2020 to July 1, 2020

Please note: Every effort has been made to ensure the accuracy of this list of donors. If you see an error or omission, please let us know.

PERPETUAL GIFT

In memory of **Ronald Clair Grafton**By Doris Grafton & Family

HONORARIUMS

JoBeth Barr

By Tracy Kalup

Robert & Juanita Collet

By Jim Joyce & Family

Carol Cordner

By James & Kathleen Cordner

Irene Joyce

By Jim Joyce & Family

Sydney & Maddie Joyce

By Bob & Juanita Collet

Donna Kalisek

By Jeff & Terri Fink

Kathryn & Fred Guenther

Elizabeth Klimchock

Phyllis Linton

By Nicholas & Linda Matteo

Drew McCoy

By Jim Joyce & Family

Kent Tekulve

By Monica Vitkay

MEMORIALS

Rose Ann Baird

By Charles & Cheryl

Lingenfelter

Robert P. Blume, MD

By Clark Hill PLC

Bob & Sylvia Danehy

Robert Downs & Family

James M Edwards

Fred & Kathryn Guenther

Michael & Judith Hannon

William Hetrick

Donna Kalisek

Kline, Keppel & Koryak PC

Robert & Kathleen Lee

Walter & Martha Meyer

Margaret Mingione

Eugene & Kathryn Polliard

William & Mary Robeson

Judy Schiffbauer

Louis & Judy Schrecker

Monica Vitkay

Peter & Alicia Zavitsanos

Rosemary Caceci

By Casper Caceci

Helen Christy

By James H. Christy

Lena Colasurdo

By Barbara Volpe

Carol Cordner

By James & Kathleen Cordner

Mary Elizabeth Evans

By William & Nancy Kukurin

Tammy Viehdorfer

Dwight & Nancy Korber

Dennis R. Felice

By Gerri Felice

Mable Catherine Gifford

By Nicholas & Linda Matteo

Rosemary Greenberg

By Robert & Nancy MacLachlan

Linda Herbold

By Stephen Herbold

James Joyce Sr.

By Jim Joyce & Family

Bessie Kalick

By Sheryl Kalick

Carol Lynn & George Sayenga

By Ed & Julianne Biehl

Matt & Michelle Sayenga

Stephanie Moorman

By Alan & Nancy Pearson

Carole Murtha

By William J. Murtha

Joyce Sarver

By Maret & Lorne Beal

Clarissa Smith

By Jerry & Margery Dudash

Norma Jean Johnson

Janelle Smith Jones

Donna Kalisek

Consuelo Nojeim

Valerie Thomas Njie

David C. Smith

Doris Specter

By Wallace Specter

Karen E. Swenson

By Kirsten Meister

Swen E. Swenson

Gretchen Wessel

MG VIRTUAL SUPPORT GROUPS

As we are dealing with the new "normal" associated with the COVID-19 pandemic, the staff at MGA recognizes that there is still a need for people to have interactions and dialogue with people who understand the complexities of their condition.

Support groups are more important than ever as they give participants a chance to discuss not only how they are feeling, but also how they are dealing with their illness during these unprecedented times.

MGA is investigating our ability to offer virtual support groups to our patients, as well as their families and friends. The idea of these groups would be to provide a safe environment to learn about MG, to have questions and concerns addressed, and to share experiences in order to support others. We would encourage everyone, including newly diagnosed and seasoned patients, their family members and friends to participate.

We are trying to determine if there is any level of interest by people to participate in these virtual support groups. If you think you would like to participate in these groups, please contact the MGA Office at 412-566-1545 or mgaoffice@mgawpa.org. Once we have a better idea of how many people may want to be involved, we will make further decisions on how the virtual support groups might be offered.



If you donate to a United Way agency in Western Pennsylvania, did you know you can designate your donation to directly benefit MGA of WPA? When making your pledge, simply designate your payment to MGA by using the following codes:

UW of Allegheny County #82

UW of Westmoreland County #1178

UW of Beaver County #4861

UW of Butler County #5981

UW of Erie County #45146

UW of Mon Valley #1178

If you are a state or federal employee and want to use payroll deduction to make a donation to MGA of WPA, please check with your employer to verify the correct codes.

UW of Washington County #0082

THANK YOU for your continued and generous support of MGA.

FALL ● 2020 Page 7

Myasthenia Gravis Association of Western Pennsylvania at Allegheny General Hospital 490 East North Avenue, Suite 410 Pittsburgh, PA 15212

RETURN SERVICE REQUESTED

Non-Profit Org.
U.S. Postage
PAID

Pittsburgh, PA Permit No. 442

SAVE THE DATE





12:00 PM - 1:30 PM
Details on pages 2
Contact Donna to Register:
412-566-1545 ot
donnak@mgawpa.org



MGA ANNUAL APPEAL GOES OUT.

DECEMBER 2020

Please give generously!





MGA HOLIDAY FUNDRAISER DECEMBER 2020

More details to follow – stay tuned!



www.mgawpa.org
and on our facebook page:
www.facebook.com/mgawpa