IWMF LIFELINE

HAVING TROUBLE REACHING A LIFELINE VOLUNTEER? NO ANSWER TO YOUR CALL? NEED FURTHER ASSISTANCE?
WE ARE HERE FOR YOU! Please Reach Out:

Lisa Wise (wiseplace@gmail.com)
Marcia Klepac (marciaklep@hotmail.com, 724-433-5687)
IWMF Office (M-F 9AM-5PM) (info@iwmf.com, 941-927-4963)

Specific Treatments

Treatment	Contact	Email	Telephone
Acalabrutinib	Rob Richardson Greg Matzen	office@iwmf.com gjbenji@gmail.com	Email only 360-273-3353
Bendamustine (solo)	Don Brown	Ldonbrown@msn.com	630-323-5894
Bendamustine & Rituxan	Lisa Wise Jack Sprankle Pam Newland	wiseplace@gmail.com JSprankle757@gmail.com mpnewland@hometel.com	Email only 937-890-2208 Email Only
CaRD (Carfilzomib, Rituxan, & Dexamethasone	Mindy Caplan	mindycap@icloud.com	504-309-2247
CAR-T	Shira Zupnick	Szupnick613@gmail.com	504-261-4445
DRC (Dexamethasone, Rituxan, & Cytoxan)	Julie Tracy Joel Rosenblit	jatrac1@pacbell.net rosenblitj@gmail.com	559-627-5471 503-365-7074
Everolimus (RAD001)	Larry Siker	admiralsiker@hotmail.com	608-774-3949 608-872-2263 608-754-3949
Ibrutinib (Imbruvica)	Erna Brout Leslie Slate Mel Horowitz Jane H	ebtge@optonline.net susanslate@aol.com wmcure@yahoo.com cmapa@comcast.net	914-713-4590 310-717-0129 518-449-8817 609-280-4659
IVIg	Peter DeNardis	pdenardis@gmail.com	724-462-9458 412-624-1092
Ofatumumab	Rob Clark	No email – calls only please	518-298-2611
Pirtobrutinib (LOXO)	Ron Ternoway Lisa Wise	rternoway@eastlink.ca wiseplace@gmail.com	1-902-997-1898 Email Only
Rituxan	Mel Horowitz Sue Herms	wmcure@yahoo.com suenchas@bellsouth.net	518-449-8817 843-801-0989
Rituxan Maintenance	Sue Herms	suenchas@bellsouth.net	843-801-0989
Management of Rituxan Reaction	Ryan Scofield	office@iwmf.com	941-927-4963
Velcade	Don Brown	Ldonbrown@msn.com	630-323-5894
Venetoclax (ABT-199)	Pat Getz Peter Horodowich Jack Honaker Barry Frank	pat_getz@yahoo.com peter@horodowich.com jackhonaker@hotmail.com bhfrank@verizon.net	505-660-2468 610-649-5694 913-617-7182 215-429-2107
Zanubrutinib	Peter Freese (Australia) Sharon Piotrowski	peterfreese@bigpond.com Sharon2girls@gmail.com	+61-429-022-665 908-727-0804
Allogenic stem cell transplant	Eileen Sullivan Melissa Sawyer	Ebsullivan27@gmail.com sawyerirish@aol.com	617-784-3397 303-883-4260
Autologous stem cell transplant	Murray Shaw Jack Honaker	murray.shaw@sympatico.ca jackhonaker@hotmail.com	613-236-5277 913-617-7182
Autologous stem cell collection	Jack Sprankle	JSprankle757@gmail.com	937-890-2208

Issues of WM Interest

Issue	Contact	E-mail	Telephone
Amyloidosis	Martin Vanderlaan Pam Newland	Sfmist@sbcglobal.net mpnewland@hometel.com	Email Only Email Only
Bing-Neel	Julie Davidson Peter Freese *Based in Australia Stuart Quick *United Kingdom	jefdavidson@icloud.com peterfreese@bigpond.com Stuartq9961@icloud.com	615-429-2017 +61-429-022-665 *Important: note time difference +44-777-426-4805
Caregiving	Susan Stoel Jeff Prupis Megan Davey	carlstoe@hotmail.com jeffprupis@yahoo.com daveym@bellsouth.net	919-285-3000 845-664-3078 901-212-8240
Cold Agglutinin Disease	Betty Usdan Pat Getz	kolbysmum@aol.com pat_getz@yahoo.com www.coldagglutinindisease.org	954-646-5585 505-660-2468
Cryoglobulinemia	Gary Green	gjgreen@cox.net	602-321-0638
Diffuse Large B-Cell Lymphoma (DLBCL)	Shira Zupnick	Szupnick613@gmail.com	516 -967- 6548
Fatigue due to WM	Marcia Klepac Pat Getz Linda Goodman	marciaklep@hotmail.com pat_getz@yahoo.com lsgood@aol.com	724-433-5687 505-660-2468 914-584-2489
Emotional aspects of dealing with WM	Wanda Huskins Naomi Schechter	lymphomation@yahoo.com naomisch44@gmail.com	845-664-3077 845-867-0693
Eye Issues in WM	Maureen Hanley. O.D.	mmhanley@hotmail.com	617-733-9043
Extramedullary Disease	Eileen Sullivan Peter DeNardis Wanda Huskins	Ebsullivan27@gmail.com pdenardis@gmail.com lymphomation@yahoo.com	617-784-3397 724-462-9458 805-664-3077
Familial WM	Marcia Klepac Wanda Huskins	marciaklep@hotmail.com lymphomation@yahoo.com	724-433-5687 805-664-3077
Hypogammaglobulinemia	Pat Getz	Pat_getz@yahoo.com	505-660-2468
Living with Vision Loss	Susan Kitazawa	plantpoems@gmail.com	415–264–7614
Lymphadenopathy/Bulky Disease	Wanda Huskins	lymphomation@yahoo.com	845-664-3077
Myelodysplastic Syndrome (MDS)/Acute Myeloid Leukemia (AML)	Murray Shaw	murray.shaw@sympatico.ca	613-236-5277
Newly diagnosed	Wanda Huskins Joel Rosenblit Charlie Davault Linda Goodman Harry Langlois Greg Matzen Suzann Albanese Naomi Schechter Sharon Piotrowski Barry Frank	lymphomation@yahoo.com rosenblitj@gmail.com charlesdavault@earthlink.net lsgood@aol.com Phone only gjbenji@gmail.com salbanese@cox.net naomisch44@gmail.com sharon2girls@gmail.com bhfrank@verizon.net	845-664-3077 503-365-7074 904-586-2952 914-584-2489 615-373-3725 360-273-3353 Email Only 845-867-0693 908-727-0804 215-429-2107
Ninety and Nifty!	Harry Langlois	Phone only	615-373-3725
Peripheral neuropathy	Tom Hoffmann Joel Rosenblit (motor neuropathy) Steve Pine	thh97@msn.com rosenblitj@gmail.com slpine001@aol.com	501-231-5667 503-365-7074 214-244-5515
Pleural Effusion	Lisa Wise	wiseplace@gmail.com	Email Only
Radiation Treatment	Eileen Sullivan	Ebsullivan27@gmail.com	617-784-3397

Relapse after Treatment	Don Brown Marcia Klepac	Ldonbrown@msn.com marciaklep@hotmail.com	630-323-5894 724-433-5687
Schnitzler Syndrome	Bernie Tyrrell	Bernard.tyrrell@gmail.com	302-740-3377
Splenic Marginal Zone Lymphoma (SMZL)	Thomas Allen	tallenph54@yahoo.com	202-596-0886
Twenty Year Club -- Thriving with WM	Fred Bickle Bob Bailey Jane Hendrickson Mel Horowitz	Flb134@msn.com Bob.bailey@W3-LLC.com cmapa@comcast.net wmcure@yahoo.com	805-492-4927 770-633-3536 609-280-4659 518-449-8817
Watch & wait	Mel Horowitz Joel Rosenblit	wmcure@yahoo.com rosenblitj@gmail.com	518-449-8817 503-365-7074
Wild Type WM	Sharon Piotrowski	Sharon2girls@gmail.com	908-727-0804
WM People of Color	Paula Eastmond	pkchika@yahoo.com	812-568-4688
Young WM	Ryan Scofield Deborah Kelly	office@iwmf.com deborah982@gmail.com	941-927-4963 713-824-5853

U.S. LIFELINE Specialty Topics

Topic	Contact	E-mail	Telephone
Affordable Care Act	Leukemia & Lymphoma Society		800-955-4572
Clinical Trials	Tom Hoffmann Greg Matzen Clinical Trial Support Center (LLS)	thh97@msn.com gjbenji@gmail.com	501-231-5667 360-273-3353 800-955-4572
Military Veterans	Charlie Davault Daniel Costigan Peter Horodowich Ray Vance Greg Matzen U.S. Department of Veterans Affairs	charlesdavault@earthlink.net dancostigan@hotmail.com peter@horodowich.com rayvanceray@gmail.com gjbenji@gmail.com	904-586-2952 952-841-0174/952-451-2339 610-649-5694 727-514-3181 360-273-3353 844-698-2311
Social Security-Disability	Daniel Costigan	dancostigan@hotmail.com	952-841-0174/952-451-2339
Holistic Wellness	Ann Grace MacMullan	anngrace@iwmf.com	941-927-4963

U.S. LIFELINE Specialty Topics

LIFELINE Languages Offered

Country	Contact	E-mail	Telephone
Arabic speaker	Sherine Elsawa	Sherine.Elsawa@unh.edu	603-862-5359 (w)
French Speaker	Murray Shaw	murray.shaw@sympatico.ca	613-236-5277
Spanish speakers	Betsy Beazley Leon Maya Brad Smith	betsybeazley@gmail.com leonmaya55@gmail.com becandbrad@gmail.com	310-428-3997 865-694-9581 808-561-7303

International LIFELINE

Country	Contact	E-mail	Telephone
Canada LIFELINE	https://www.wmfc.ca/support/canadian-lifeline/		
UK LIFELINE	www.wmuk.org.uk/about-wm/links		

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Marcia Klepac (marciaklep@hotmail.com, 724-433-5687)
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