



## PRESIDENT'S MESSAGE

by Randy Yudenfriend Glaser

This past year has been a very exciting one for the Foundation. With the finding of the gene, carrier testing has been made available to the general Jewish population. The carrier test has been added to the list of Jewish genetic diseases for which one can be tested prenatally.

This past summer I was asked to speak at Genzyme Diagnostics near Boston, one of the largest diagnostic companies. I spoke to a meeting of lab technicians and genetic counselors in order to give them a more personal understanding of the effects of the test on family members. Genzyme attempts to take their staff out of the "test tube" and give them a more personal experience which seems to enhance their commitment to their work. I was honored to be part of this successful work which was a dream just a few years ago. Genzyme performs carrier testing for many institutions and physicians.

The carrier test is also available at Mt. Sinai Medical Center in NYC, Henry Ford Medical Center in Detroit, Gene Dx in Maryland and St. Barnabus Medical Center in New Jersey. The proper procedure is to speak to your physician and ask the lab that he/she sends you to to perform the ML4 carrier test along with the others you choose.

My travels for the Foundation also brought me to the National Institutes of Health in early October to speak at a symposium in celebration of Dr. Roscoe O. Brady. (see article on page 7) This was a tremendous honor since the ML4 Foundation and NORD (National Organization of Rare Diseases) were the only two Foundations represented. Dr. Brady was the first contact we had at the NIH in the early nineties. He met with a few families and children and assured us that there would be a carrier test by the time our younger children were ready. Dr. Brady is a man of his word.

I spoke about Dr. Brady's support of the Foundation and unlike many of the other diseases which were spoken about by the President of NORD, that ML4 is still attempting to develop a

mouse model in order to proceed with treatment possibilities. Dr. Brady's support of ML4 research was duly praised and yet I encouraged continued support as recommended in the Congressional Report.



We have reached a critical point in ML4 research where the next step is to elucidate the function of the ML4 gene and once that is accomplished to attempt treatment to correct the dysfunctional gene.

The road ahead is not an easy one, and not inexpensive. The cost of one mouse model approaches \$50,000.00. We have remained committed to this research and our goal is to continue to fund scientists who have dedicated themselves to ML4 research.

I continue to receive phone calls from desperate families whose children are misdiagnosed. Their children are not infants, they are already 4-5 years old. The medical community continues to remain uninformed as concerns ML4 and our goal for this year is to change this situation.

We presently fund research at Brigham Women's Hospital/Harvard and John's Hopkins Medical Center. (see article on page 1) We work closely with the National Institutes of Health and the prospective clinical study continues there.

I want to take this opportunity to thank you for your continued support and for helping the carrier test for all of our children to become a reality.

Wishing you all a happy and peaceful New Year!

Randy Yudenfriend Glaser  
President, ML4 Foundation