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RWRM'S GOAL FOR AN AYA BLOOD CANCER CENTER TEAM AND CERTIFICATION

(October 2008)

- 1) RWRM believes that AYA (Adolescent and Young Adult) blood cancers are a very specific category of the AYA problem. More so than other forms of AYA cancer, blood cancers and their treatments are often extended over years or decades, and the treatment modalities are especially controversial, expensive, experimental, difficult, life-threatening and even when successful, daily life-altering - specifically bone marrow/stem cell transplanting.
- 2) RWRM suggests the formation of a "Team" of experts that would develop the criteria for a "Certification" for "AYA Blood Cancer Treatment Centers". These criteria would be listed and the Certification would only be granted after a Center showed that it met the criteria.
- 3) While the Team must develop these criteria, the criteria would be things such as:

*The Center must have a named physician oncologist who would be charged with making sure that any AYA patient presenting to the Center would be considered for pediatric or adult protocols. The oncologist would be charged with discussing that issue with the patient and his family.

*The Center must have a written policy on informed consent and confidentiality dealing with how it will recognize parents, siblings, other family members, and significant others as part of a team during the long course of treatment.



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*The Center must have age specific fertility counseling in accordance with standards such as those adopted by FertileHope.org. ...

The Team would develop a list of 10 or 15 such criteria.

- 4) The Certification could either encourage or require any Certified Center to have a paid, year-long Fellowship, where a Fellow would be recruited to work with the transplant teams to learn to treat AYA patients. If this could be started at even 5 or 6 centers nationwide, the entire system of treatment would change as these doctors made their way into practice. The cost of such a fellowship would be split between locally-constructed groups of philanthropists and Foundations and the resident hospital. As this produces "graduates" over several years, it would be a wonderful seeding of experts into practices throughout the country.
- 5) RWRM anticipates that, initially, only 3-5 Centers would qualify for Certification. At the start, a small number in geographically dispersed areas might be preferable because blood cancers in this age group are relatively rare. These Centers would serve as magnets drawing patients regionally which would benefit these dedicated centers enormously (both through experience and financially) and the patient (because the Centers would become very good at treating AYA patients). Perhaps most importantly, they would become models that other hospitals could copy.
- 6) The Team should discuss if the certified institutions could form a protocol study group, in the nature of CCG (Children's Cancer Group) and ECOG (Eastern Cancer Oncology Group), etc., in order to share experiences and develop new studies, or to work with the already organized (CCCG) Coalition of Cancer Cooperative Groups.
- 7) RWRM is exploring if this initiative could be tied in with the Lance Armstrong Foundation, the National Cancer Institute, and The Leukemia and Lymphoma Society, giving even more weight to the Certification.



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- 8) RWRM believes that these initiatives would jump-start and support the efforts in these specific Beta Sites and be a true feather in the cap for any sponsoring organization as well. For the first time, AYA patients diagnosed with leukemia, lymphoma, Hodgkin's, etc., would have some way to make an intelligent choice of where to seek treatment.
- 9) Equally important for success would be the value to each certified Center in being able to advertise its Certification in this area. If LAF would come on board, it is very credible amongst young people. Once the Centers realize that this is a very marketable designation, the institutions will be more willing to budget the funds necessary to meet the certification requirements, to the benefit of all.
- 10) Most importantly, each PATIENT, going forward and building on the experiences of the last patient, would benefit by having a directed, specific focus on the needs of AYA patients facing a hematologic malignancy. If the initial centers are successful, eventually, every cancer center in the country would benefit by trying to emulate the Center's receiving the initial designation.