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RWRM's Contribution to Lance Armstrong Material to National Institutional Review Boards

A major stress event for each AYA patient is immediately upon diagnosis. At that shocking, sad and stressful moment, many younger patients are not prepared to process the mass of information thrown at them. Many of them have never even considered their own mortality let alone treatment choices with far reaching side effects. Many are too sick or confused to focus on details at that very moment when critical choices must be made, including enrollment in one or another clinical trial. At those moments of decision, the younger patient may not want to be alone. He may need to have his unique "team" available to consider and advise him. In today's world, that team might include a parent, or a close friend, or a boyfriend or girlfriend.

On the other hand, the doctors and the hospitals must act quickly. They also must respect the rights of privacy of the patient. If the patient is 18 or over, frequently, the doctors or nurses immediate reaction is to ask members of the team to leave during tests or discussions, often while citing HIPAA, or other legal concerns. These concerns may be valid as well since there is possible legal liability if private information is disclosed, and many doctors want to make sure that the patient himself is totally on board with the choices.

Making matters more difficult, many times the AYA patient agrees to having his team excluded from the room or from getting information because they really don't want to "rock the boat" with those providing the care. They view the doctors and nurses as their lifeline and they don't want to argue or "look stupid", even if they are very scared to face these decisions and choices on their own.

A valuable tool to solve all of these concerns is the use of a Power of Attorney. In a written Power of Attorney (POA) the younger patient should be able to name the people he wants to receive his healthcare information, be present during tests and discussions, and advise him before making any final decisions. The POA can be signed in multiple copies and given to multiple care givers. It can be drafted so that it is valid indefinitely until it is revoked. In this way, the hospital, doctor and nurses can be on the same page as the patient, without needless confusion or fear of violating privacy laws. (While POAs like this are generally enforceable, the rules regarding POAs do vary from state to state.)

It would be extremely valuable if IRBs would suggest the use of Powers of Attorney for AYA patients who are first diagnosed with cancer and being advised of clinical trials. By recognizing the young patient's chosen "team" right at the beginning, the interests of both the doctors and the patient can be served. Most importantly, the AYA patient can be relieved of feeling in the middle and alone at the most important decision-making time of his life.