

## February 2010 Meeting News –

### New Members

Allen was diagnosed September 2008 after two vertebrae fractures and spine compression. After six months of Revlimid, he had a transplant at Northside in May 2009. The disease returned in November and he is on Velcade and Dex. Jennifer was diagnosed in October 2009 after a cracked rib and fatigue. She has had four rounds of Velcade, Revlimid, and Dex.

### Business & Other Information

Guest speaker was **Bruce Johnston**, who now helps people obtain disability benefits privately after a career with Social Security disability. She understands the challenges of a serious disease as her son has CML. He recently had his annual biopsy and got the all clear and no tests for two years. Bruce explained that there are two types of disability. Title II which is paid through FICA taxes withheld from wage earners. The benefits are for wage earners, their widows or widowers, and the children of wage earners. The disability amount is determined by the amount paid in to FICA taxes. The other type of disability is Supplemental Security Income (SSI) which has been around since 1973 and is paid from general tax revenue not Social Security benefits. There is a low income disability under Title 16, but certain levels of income and resources are a pre-requisite to qualify. Georgia, if you are entitled to SSI, then you are also eligible for Medicaid benefits, if you do not qualify for Medicare. Under Title II, Medicare benefits are available after a 29 month waiting period. If you are on regular Social Security after age 65 or on Medicare, you cannot qualify for SSI. The definition of disability is that you can not engage in substantial employment for 12 months. For example, if you are diagnosed and undergo treatment where you can not work for one year or more, you are encouraged to make application to SSI at the time of diagnosis or soon thereafter. If you are under age 65 and take early retirement benefits, SSI benefits will be increased to the full retirement level. Application for SSI can be done in person or online. Prior to application, collect all doctors' names, hospitalization dates, medications, and work history. Be sure to include any other conditions including emotional issues and treatment side effects, such as fatigue and memory lapses. The claim adjudicator will contact all medical sources to collect records. The patient may also be contacted to describe conditions. An online reference provides medical requirements and a list of all conditions that meet disability criteria. Other considerations include age and education and type of work. Once you are on SSI, benefits cannot be terminated until the agency proves the improvement of the medical condition. Be sure to respond to any queries from SSI when you are on disability.

### Member Updates & Collaboration

**Jeanette** cracked a rib October 2009 and is dealing with constant fatigue. She has had four rounds of VRD (Velcade, Revlimid, and Dex). **Ginny** is still on Pomalidomide at a lower dose than the clinical trial. She is on her third cycle. Pomalidomide is now in Phase 2 clinical trials at Emory. **Mike** found a lesion last August that was treated with radiation. He is now on Dex, 40 mg, 4 days on and 4 days off. He has completed three cycles of just Dex. **Carolyn** is in Phase 2 trial of Hulac with a longer infusion. She is also taking Benedryl and Tylenol for side effects. **Latain** is in her fourth cycle of Dex, Velcade, and Thalidomide which has brought her into remission. She is considering a transplant since she had two and a half years of remission with the last one. **Gail** had a transplant December 2008 and is

dealing with neuropathy from Velcade. She is taking neurontin and oxycontin to handle the pain. **Pat** is also having severe neuropathy from Velcade and taking neurontin. **George** was taking Thalidomide and the neuropathy got worse. His pain went away after an exercise program and now runs two miles per day. **Sandy** had her infection cleared with a round of antibiotics and had her port removed that had been in for ten years. The group was pleased to see **Vanessa** after her transplant on January 13. She was doing well and admits that she has had to slow down. **Hector** has had a port installed for rounds of Velcade, Revlimid, and Dex. **Mike** is still holding remission since September after six months of Revlimid.

**Submitted by Nancy**