



## Advocacy Update

VHL Family Alliance Annual Meeting  
June 28, 2008  
Orlando, Florida



## Advocacy Update

- Genetic Information Nondiscrimination Act
- Comprehensive Cancer Care Improvement Act
- Small Business Innovation Research/Small Business Technology Transfer Reauthorization Act
- Consumer Taskforce on Genetic Testing
- Be Your Own Best Advocate!



## Advocacy Update

### Genetic Information Nondiscrimination Act (GINA)

- H.R. 493 (Slaughter, D-NY), S. 358 (Snowe, R-ME)
- This legislation would prohibit discrimination on the basis of genetic information with respect to health insurance and employment. GINA provides strong, enforceable protections against the misuse of genetic information—the definition of which includes family health history—in both health insurance coverage and employment decisions.
- Passed the House of Representatives (415-3), Passed Senate (95-0)
- Signed by President on May 21, 2008 – billed as the first piece of civil rights legislation in the new millennium
- VHLFA part of the Coalition for Genetic Fairness



## Advocacy Update

### Comprehensive Cancer Care Improvement Act

- H.R. 1078 (Capps, D-CA), S. 2790 (Landrieu, D-LA)
- Sponsored by the National Coalition for Cancer Survivorship
- The CCCIA includes a number of proposals that would advance a system of integrated cancer care and improved communication between patients and their health care teams regarding treatment options and follow-up care. By reforming Medicare reimbursement, enhancing training of professionals who treat cancer survivors, and testing and expanding model systems of integrated care, the Act would advance a system of quality, comprehensive cancer care
- Visit with your Congressional representatives while they are at home during the July 4 recess – June 30 through July 6 and ask for their support



## Advocacy Update

### Small Business Innovation Research/Small Business Technology Transfer Reauthorization Act

- H.R. 5819 (Velazquez, D-NY)
- The SBIR/STTR provides for special considerations to be given by the Food and Drug Administration (FDA) when conducting work on rare diseases
- Concerns have been expressed about providing some mechanism for accountability to FDA for firms who may subcontract some part of manufacturing or research process where related to rare disease programs
- Passed the House and is in the Senate Committee on Small Business and Entrepreneurship



## Advocacy Update

### Consumer Taskforce on Genetic Testing

- Formed by Genetic Alliance in 2006, the Taskforce exists to provide consumer perspective and input to federal agencies regarding genetic testing regulations and rules
- Participated in Genetics Day on the Hill
- Participated in Genetic Testing Summit in September 2007
- VHLFA represented on Taskforce



## Advocacy Update

### *Be Your Own Best Advocate!*

- VHLFA cannot lobby, but you can!
- Develop a report with your local elected officials and representatives
- Write letters, make phone calls, educate your friends, neighbors and community about VHL and your experiences
- There is no stronger voice than the voice of experience and your personal challenges and triumphs with VHL carry a lot of weight!

Get involved with the VHL Family Alliance  
There's strength in numbers!



## Thank You!

Camron King  
camron94@yahoo.com  
[www.vhl.org](http://www.vhl.org)