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Ideas for a Changing National Institutes of Health

The non-profit NephCure Foundation is the only organization dedicated exclusively to finding a cure for focal segmental glomerulosclerosis (FSGS) and Nephrotic Syndrome (NS), devastating kidney diseases that often attack children and young adults. Founded by patient families in 2000, NephCure has partnered with top scientists investigating these diseases and in 2008 alone committed \$2 million in funds for such research.

NephCure has partnered with the National Institutes of Health (NIH) to create a matching grant program for research into FSGS, which involves the scarring and destruction of the kidney filtering mechanisms. (FSGS gained some visibility when NBA star Alonzo Mourning lost his kidneys to the condition.) FSGS often is linked with Nephrotic Syndrome, the condition in which valuable proteins escape from the kidney into the urine.

These diseases exact an enormous public toll and have a disproportionate effect on the African-American community. There is no known cause of primary (idiopathic) FSGS and no proven treatment for primary FSGS or FSGS secondary to diseases such as Lupus and HIV. The economic cost of kidney dialysis for FSGS patients is approximately \$3 billion a year. Kidney transplantation is not a sure-fire answer; in 30 to 40 percent of such cases FSGS returns to the new kidney and the human suffering resumes.

In 2008 there were 19,306 people with End Stage Renal Disease (ESRD) as a result of FSGS, making it the second leading cause of kidney failure among children. But tens of thousands of other patients are in the painful FSGS and NS pipeline leading to ESRD. The federal investment in medical research must be increased substantially and in a systematic fashion to ensure that innovative discoveries are translated to patient-aiding treatments in a timely manner.

Minority populations affected by NS and FSGS can be difficult to reach, often not responding to traditional modes of outreach. NephCure recommends that new methods of minority outreach be explored and utilized by NIH to increase community awareness in the African American community.

NephCure will launch in 2009 a concentrated effort to reach out to African-American populations to promote awareness and create programs that promote better diagnosis of FSGS and NS. NephCure embraces the use of faith-based initiatives within the African American community to combat health disparities.

A NephCure board member already has worked with her African-American church to develop a urine protein loss screening program for children in the congregation. This simple tool can detect Nephrotic Syndrome.

NephCure thinks that an expanded initiative to increase awareness and diagnose NS and FSGS within minority populations, particularly African Americans, might best be initiated through the faith community with assistance from federal partners such as the NIH.