

Sultanov, of Kazakhstan's Institute of Strategic Studies, worries that "our border troops cannot carry out any operations because there is no legal basis for them."

Last year, Uzbek border guards entered southern Kazakhstan and claimed a stretch of land. Since then, there have been several brushes between Uzbeks and Kazakhs, mostly villagers unclear about which country they are living in. All this is a distraction from the task of making the south of Kazakhstan more secure.

Then there is Afghanistan. Although Kazakhstan is not a direct neighbour, the fiercely Islamic Taliban who control most of Afghanistan are a worry to all of Central Asia. They are believed to provide training for extremists, among them the Islamic Movement of Uzbekistan (IMU), which wants to set up a caliphate in the Fergana valley, where Kirgizstan, Tajikistan and Uzbekistan meet. The IMU was said to be behind the attacks in Kirgizstan and Uzbekistan in the past two years and is thought to be preparing another assault before long.

Most of Kazakhstan's military equipment dates back to the Soviet period. Replacing, say, old helicopters used in the border areas will be expensive, but necessary. In January a Mi-8 helicopter crashed in the south, injuring the defence minister, Sat Tokpakbaev, who was aboard. Another helicopter crashed near the Chinese border two weeks ago, killing six people.

Kazakhstan will receive arms from Russia worth \$20m this year as part of its annual payment for the use of a space-rocket site at Baikonur. It is due to receive over \$4m from the United States to improve border security. The government might also consider some nonmilitary measures. Government repression and mismanagement help to nourish extremism and terrorism in Central Asia. An effort to improve social and economic conditions and freedom of expression might make Kazakhstan less fertile ground for militant zealots.

TESTIMONY OF DR. IRVING
SMOKLER

HON. LYNN N. RIVERS

OF MICHIGAN

IN THE HOUSE OF REPRESENTATIVES

Wednesday, April 4, 2001

Ms. RIVERS. Mr. Speaker, I would like to share with my colleagues, the testimony of Dr. Irving Smokler, presented to the House Appropriations Subcommittee on Labor, Health, and Human Services, Education and Related Agencies. Dr. Smokler is the president of the NephCure Foundation and testified regarding the need for increased funding for research and raising professional and public awareness on glomerular injury through the National Institute of Diabetes and Digestive and Kidney Diseases.

TESTIMONY REGARDING FISCAL YEAR 2002 FUNDING FOR NATIONAL INSTITUTE OF DIABETES AND DIGESTIVE AND KIDNEY DISEASES Presented by Irving Smokler, Ph.D., President of the NephCure Foundation, Accompanied by Brad Stewart to the House Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies—March 20, 2001—10:00 AM SUMMARY OF FY 2002 RECOMMENDATIONS

1. Continue the effort to double funding for the National Institutes of Health by providing an increase of 16.5%, to \$23.7 billion for FY02. Increase funding for the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) by 16.5% to \$1,518,443,525 for FY02.

2. Prioritize glomerular injury research at NIDDK (including clinical trials), raise professional and public awareness about glomerular injury, and encourage more aggressive scientific attention to all kidney diseases.

3. Urge NIDDK to develop programs to attract talented researchers to the field of glomerular injury.

Mr. Chairman, and members of the subcommittee, I am pleased to present testimony on behalf of the NephCure Foundation (NCF).

We are a relatively new, non-profit organization with a mission of supporting research and public awareness on glomerular injury, which is related to the filtering mechanism of the kidney. I serve as president of the foundation, and have a son, who has had a glomerular disease since he was eleven months old. Although he is now 24 years old and in remission, eighty percent of those in his situation lose their kidneys or their life by the age of five.

What is glomerular injury?

Mr. Chairman, each kidney contains about one million tiny filtering units called nephrons. Nephrons are the key to the kidney's filtering function, processing a constant flow of waste-laden blood, sorting out the vital fluids, from the toxic and unnecessary elements.

When someone suffers from a glomerular disease, this vital process is impaired. In some instances, an individual will lose protein and sometimes red blood cells in the urine, have high cholesterol levels, and experience severe swelling in the body from too much fluid. Incidence of this disruptive Nephrotic Syndrome is increasing, and this perplexes physicians who cannot identify the cause or cure.

Sometimes damage occurs to the nephrons, specifically, scarring of the glomeruli, which are microscopic capillaries in the nephron. The severe form of this glomerular injury is Focal Segmental Glomerular sclerosis (FSGS). Presently, there is no treatment to reverse this damage. FSGS can lead to end stage renal disease—total, or near total, permanent kidney failure. Costly dialysis treatments become necessary and kidney transplants may be required for severe cases.

The toll of glomerular injury

Glomerular injury affects tens of thousands of patients in the nation, most of them young. While it is unclear exactly how many Americans are impacted, the incidence of glomerular injury is on the rise. Severe forms of glomerular injury are costly to diagnose and treat, and at this time the only relief for these patients is with heavy medi-

cation, usually steroids, which have strong and unpleasant side effects and only work for about 30 percent of patients.

Problems of misdiagnosis often occur with glomerular injury. Most patients and parents have stories about the unusual length of time between the first symptoms and diagnosis. The early signs of glomerular injury, swollen eyelids, are often mistaken for allergic reactions. Health care professionals don't appear to be fully knowledgeable about this disease.

The physical changes, extreme swelling of the face and body, can adversely affect all aspects of a young person's life. With a stronger commitment to research and educational awareness, suffering can be minimized and hopefully eliminated.

There is hope for scientific breakthroughs

At a meeting co-sponsored by the NephCure Foundation, preeminent scientists from around the world have shared their findings about the podocyte, a major filtering cell, with tentacle-like feet. The relationship between the podocyte and the glomerulus may be a key to understanding glomerular injury.

Recently, researchers have discovered certain molecules that are essential to the podocyte's function. As this becomes better understood, scientists are hopeful of finding better ways to treat glomerular diseases, and prevent their progression to more grave conditions.

This spring, NIDDK will begin to establish clinical trials, which will test various treatments for hundreds of FSGS patients. But there is a need for more funds to strengthen the basic science behind these studies. Researchers need to study tissue and fluids from those patients to advance their knowledge of the molecular causes of FSGS.

What needs to be done?

Respectfully, Mr. Chairman, the NephCure Foundation urges this subcommittee to:

1. Continue the support for doubling the National Institutes of Health (NIH) and the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK).

2. Provide the funding and recommendations for the National Institute of Diabetes and Digestive and Kidney Diseases to aggressively pursue a scientific program which will advance research into glomerular injury, conduct clinical trials, raise public awareness, and recruit talented scientists to this field of research.

Thank you for the opportunity to appear before you today.

Mr. Chairman, we hoped to have Melanie Stewart here to testify today, but her health would not allow her to be here. Her father, Brad Stewart, will read Melanie's statement.

My name is Melanie Stewart. I'm 13 years old and have had FSGS since I was six. Until a year ago I spent most of my life in the hospital or hooked up to a dialysis machine for 8 hours every day. My kidneys finally died last year, so my dad gave me one of his. I've done my best to keep it by taking 20 pills a day, fighting off infections, hemorrhages, and a blood clot in my heart. The kidney my Dad gave me is failing.

There are thousands of kids just like me who would like a change at a normal life. For all of us, I'm asking for your help in finding a cure for this disease.

Thank you for listening.