

NephNews

Kidney Disease Research

WINTER 2016

VOLUME 1 ISSUE 1



Welcome to the first issue of NephNews: dedicated to keeping you informed about kidney disease.

At SickKids, we are constantly looking for ways to improve our interactions with patients and families. This is why we created NephNews: to give you an inside look into our division on a quarterly basis. Our goal is to educate, inform, and inspire our families about kidney-related topics and issues.

Delivering the highest quality care to patients is our number one priority. To do this, we need to stay up-to-date on current advances in the field of kidney care. At SickKids, we engage in cutting-edge research to improve our understanding of kidney diseases, and ways in which we can prevent, detect, and treat these diseases. Our hope is that by shedding light on some of the research we have been doing, and how our care of patients has been transformed as a result, we will inspire our patients and families to participate in our research projects. With more children involved, we can do better research, and ultimately help more children with kidney disease receive the best possible care.

We hope you find this newsletter interesting and informative. We encourage you to share your thoughts and feedback about this newsletter with us, so that we can improve our content based on what is important to you.

Dr. Lisa Robinson, Division Head, Nephrology

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Spotlight on Henoch-Schonlein purpura

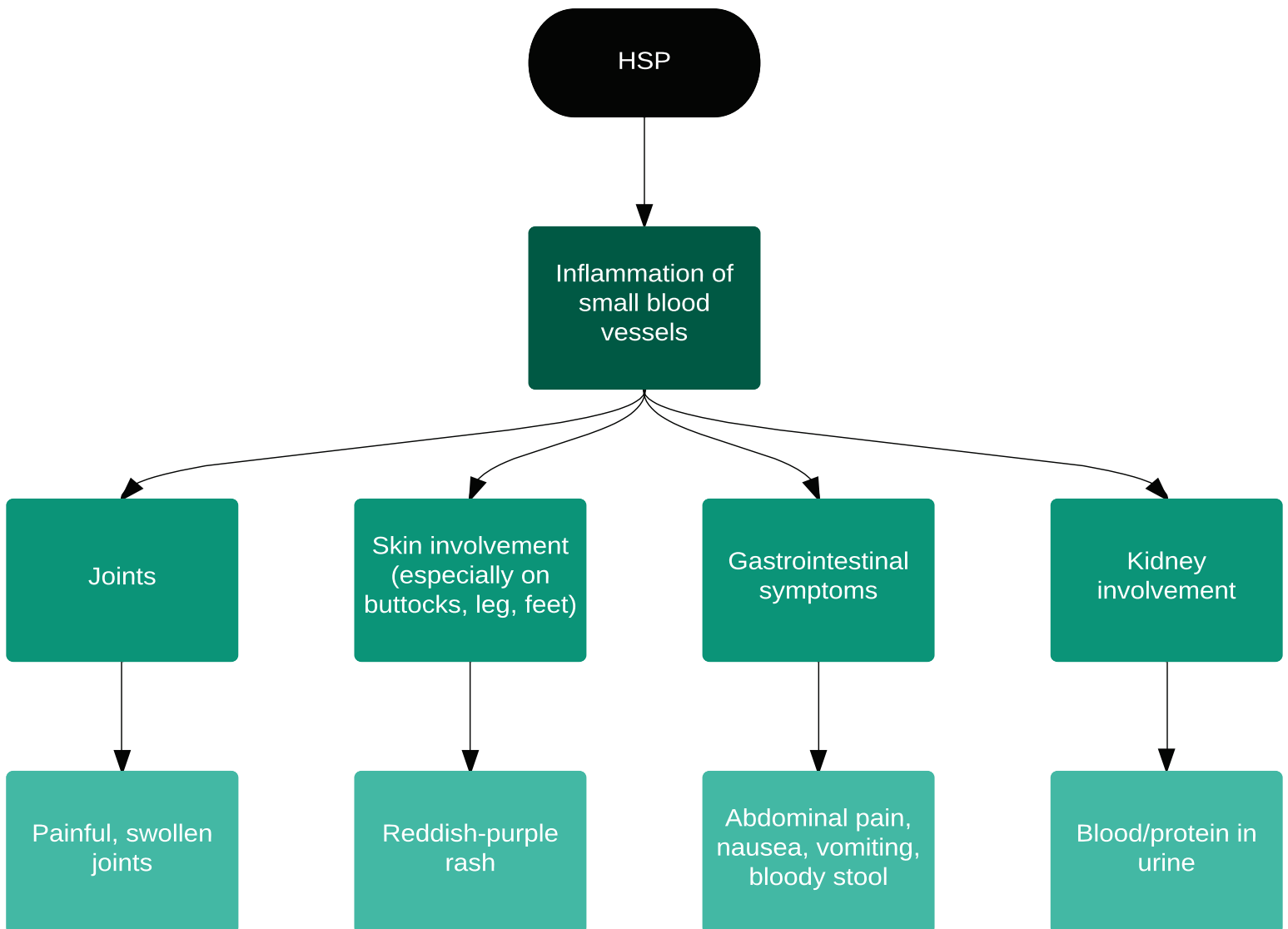
Quick Facts:

- HSP is a childhood disease that affects blood vessels, and causes swelling (inflammation)
- Diseases that affect the whole body are called systemic. HSP is the most common systemic inflammatory blood vessel disease of childhood (10-20/100,000 children per year).
- A protein that travels in the blood attaches to the blood vessels in the skin, joints, intestines, and kidneys. The protein causes the blood vessels to swell and bleed.
- HSP can occur at any age, but typically onsets in children 2-6 years old.
- HSP often follows an upper respiratory tract infection.
- Most children recover completely within 8 weeks--in rare cases, some children relapse or have long-term damage to the kidneys.

While rare, HSP can cause permanent kidney damage. This damage can cause blood or protein in the urine. Sometimes severe kidney damage requires dialysis or a kidney transplant. About half of older children with HSP will have kidney involvement. It is only serious in one out of ten children and only 2-5% of children need dialysis or a transplant.

Kidney function must be closely monitored in HSP patients to help prevent permanent damage. A child's urine is monitored for blood and protein for 12 months after they have been diagnosed with HSP. It is also important to monitor blood pressure because high blood pressure, a common side-effect of HSP, can cause kidney problems as well.

There is no cure for HSP. Treatment includes monitoring the child for kidney-related complications and making sure that they are drinking enough water to stay hydrated.



SickKids first in North America to use hemodiafiltration

The Dialysis Unit is proud to announce that hemodiafiltration (HDF) is now in use. SickKids is the first North American pediatric institution to be using HDF.

Purpose of dialysis

The kidneys are important for filtering blood. Without proper kidney function, small molecules (solutes) build up in the blood, causing problems for the affected child. Dialysis is an external device that filters blood. It is used when a child's kidney fails.

Problems with conventional hemodialysis

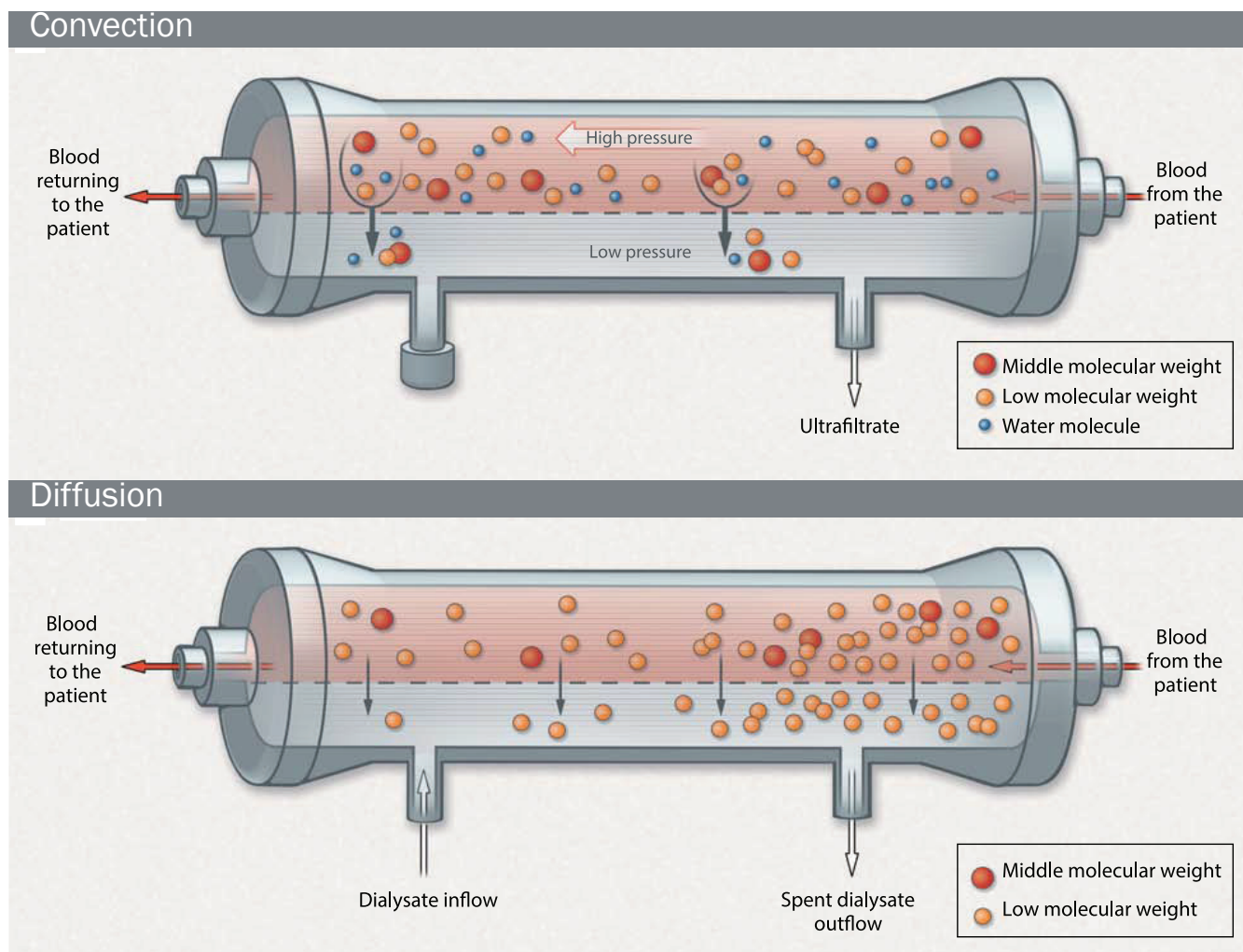
Conventional hemodialysis (HD) uses diffusion (movement of molecules from areas of high concentration to areas of low concentration, i.e., down a gradient) to remove solutes from blood. However, middle- or large-sized molecules remain trapped in the blood. Conventional HD is also exhausting for the child, and can affect their ability to concentrate.

HDF vs. conventional HD

HDF offers significant advantages to children requiring kidney replacement therapy. By combining diffusion (clearing blood by removing particles through the use of gradients) and convection (clearing blood by removing particles through the use of pressure and flow rates), HDF is able to offer greater clearance, reduced swelling, and many other benefits to the child. This results in a great improvement in the child's growth, energy, and cardiovascular health.

Studying the differences

We are exploring the differences in how HDF and HD affect growth and cardiovascular health. This research will help us to determine the most effective treatment for our patients, and to understand the effects of this new system on the children we treat.



Transport of small molecules in the blood via convection (top) and diffusion (bottom). Figure adapted from Tolwani, A., Continuous Renal-Replacement Therapy for Acute Kidney Injury. *New England Journal of Medicine*, 2012. 367(26): p. 2505-2514.

Upcoming learning opportunities



Chronic Kidney Disease Family Meeting
Spring, 2016

INSIGHT Family Meeting
Spring, 2016



Manulife Kid Science

Manulife Kid Science is an outreach program offered by the Research Institute at The Hospital for Sick Children. The program, instituted by Dr. Lisa Robinson, Nephrology Division Head, aims to provide at-risk middle- and high-school students, and those without equitable access to science experiences, with an opportunity to improve their understanding of science and technology. The hope is that these children will be inspired to make positive educational and career choices for their future.

The program is offered to patients receiving medical care at SickKids, youth living in priority neighbourhoods within the Greater Toronto Area, and youth from remote communities in Ontario. To date, this effort has reached over 10,000 students.

Kid Science encompasses seven types of programs:

1. Career Workshops--medical school, engineering, and nursing workshops
2. Lab Visits--biomedical research laboratory visits
3. Science Extravaganza--annual science symposium
4. Science Workshops--experiments on a variety of science topics
5. Speakers Bureaus--science professionals share their experiences
6. Manulife Kids TV Show
7. Summer Mentorship--assisting in research

For more information on this program, please contact:
kidscience@sickkids.ca



Kidney research at SickKids

In the Division of Nephrology, we are committed to giving our patients the highest quality care. This means that we need to continue to broaden our understanding of kidney diseases, their causes and treatments, and their implications on overall health and well-being. In order to do this, we conduct research studies. The information that we uncover will help us to better care for children with kidney disease in the future. But without participants, we simply cannot do this research. We need your help!

Within the division, there are several ongoing studies, and more that we plan to start up in early-2016.

Eculizumab Treatment Follow-Up Study

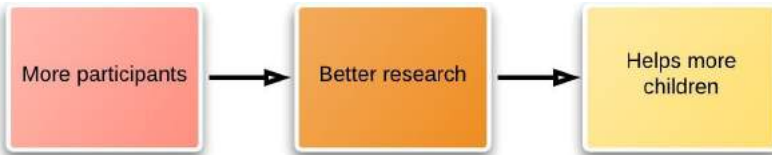
SickKids was one of many sites involved in a drug treatment trial to test the effectiveness of the drug eculizumab in the treatment of atypical hemolytic uremic syndrome (aHUS). The drug was found to be effective, and is currently the only available treatment option for those with aHUS. Now, we are keeping track of all those who were

treated with eculizumab, to see its long-lasting effects over time.

Patient Registries

Our patient registries are some of our biggest resources when doing research:

- Registries help identify which children can help us to answer our research questions in the best way possible
- Our goal is to enroll every child into a comprehensive registry (called TRACKiD) with their basic diagnostic information to:
 - » Keep track of each one of our patients, and
 - » Know which children will be eligible for future research studies



Get involved: participate in our research studies

If you have been diagnosed with:

Atypical Hemolytic Uremic Syndrome,
IgA Nephropathy,
Glomerulonephropathy,
Rare Kidney Stone Disease,
Nephrotic Syndrome,
or Renal Dysplasia

or if you are currently undergoing dialysis

you may be eligible for one of our research studies.

Please contact nephrologyresearch@sickkids.ca
if you are interested in learning more about participating in research.

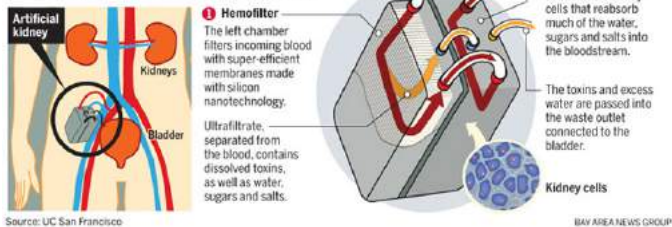
Kidney research around the world

Artificial kidney

Development of a surgically implantable, artificially kidney is underway at the University of California San Francisco. This artificial kidney--the size of a coffee cup--represents an alternative to dialysis or kidney transplantation in patients suffering from end-stage renal

Implantable artificial kidney

UC San Francisco is heading a team of researchers around the country who are working to create an implantable, artificial kidney the size of a coffee cup. The device consists of two chambers:



disease. The project recently received a \$6 million grant from one of the National Institutes of Health (NIH) to conduct clinical trials.

Maintaining fluid levels after transplant surgery

Maintaining adequate hydration is vital for the kidney to function properly after transplant surgery, but this is often difficult to manage and monitor in children. A study has now shown that using the HydraCoach water bottle--which calculates personal hydration needs and monitors fluid intake--helped with fluid consumption in children who had undergone kidney transplantation, and was more effective than standard education at increasing patient's fluid consumption.

Kidneys in the news

Zimbabwe to offer kidney transplant operations

- Kidney transplants were once offered to patients with end-stage renal disease in Zimbabwe; but following the discovery of an overwhelming number of HIV cases in 1992, kidney transplants were stopped and resources diverted to the fight against HIV.
- Now, Zimbabwe is geared up to resume kidney transplantation.
- The project will ultimately save huge amounts of money in transportation costs, as patients will no longer have to travel to other countries for care.
- The Chitungwiza Central Hospital and Johannesburg General Hospital plan to perform their first kidney transplants in early 2016.

New test may predict future kidney disease

- Researchers at Emory University have discovered a biomarker in the blood that can help to predict patients at risk for kidney disease, before the kidney is irreversibly damaged.
- The biomarker, soluble urokinase-type plasminogen activator receptor (suPAR), is elevated in those who will go on to develop kidney disease over the next five years (40% of people with elevated suPAR levels developed kidney disease).
- Early detection of such biomarkers can prompt lifestyle changes that can delay or halt the onset of disease.

New drug to treat acute kidney injury

- NephroGenex, Inc. has announced that the U.S. Food and Drug Administration has cleared the new drug, Pyridorin, to be clinically tested for the treatment of acute kidney injury (AKI).
- AKI is a severe illness characterized by a sudden decline in kidney function, which can sometimes lead to lasting kidney damage.
- Preclinical studies have shown that the drug works by enhancing recovery of kidney function and reducing scarring.



Kidney-friendly recipes

Low Potassium Hummus

Recipe from Andrea Aquilina, Dietician, The Hospital for Sick Children

Ingredients:

1 medium cauliflower, cut into florets
1/4 cup olive oil
1 garlic clove
1/3 cup tahini
3 tbsp lemon juice
1/2 tsp salt, divided

Directions:

Toss cauliflower with 2 tbsp olive oil and 1/4 tsp salt. Spraed out on baking sheet and bake at 400°F for 30 min, stirring halfway through. Cool. Combine with garlic, tahini, lemon juice, 2 tbsp olive oil and remaining 1/4 tsp salt in a food processor. Whirl until smooth. Serve with pita bread and fresh veggies.

Peach Smoothie (low potassium, low phosphate)

Recipe from Andrea Aquilina, Dietician, The Hospital for Sick Children

Ingredients:

1/2 cup frozen peaches
1 cup (250 mL) rice milk, preferably not enriched (comes in a tetra-pak)
1/2 tsp almond extract
3 ice cubes
1 tsp white sugar (or more to taste)

If your child is trying to gain weight, also add 1 tbsp vegetable oil.

Directions:

Put all ingredients in a blender. Process on high speed until smooth. Divide evenly into two glasses. Serve right away, or save the unused portion in the fridge and blend it again before using.

Low Sodium Beef and Veggie Soup

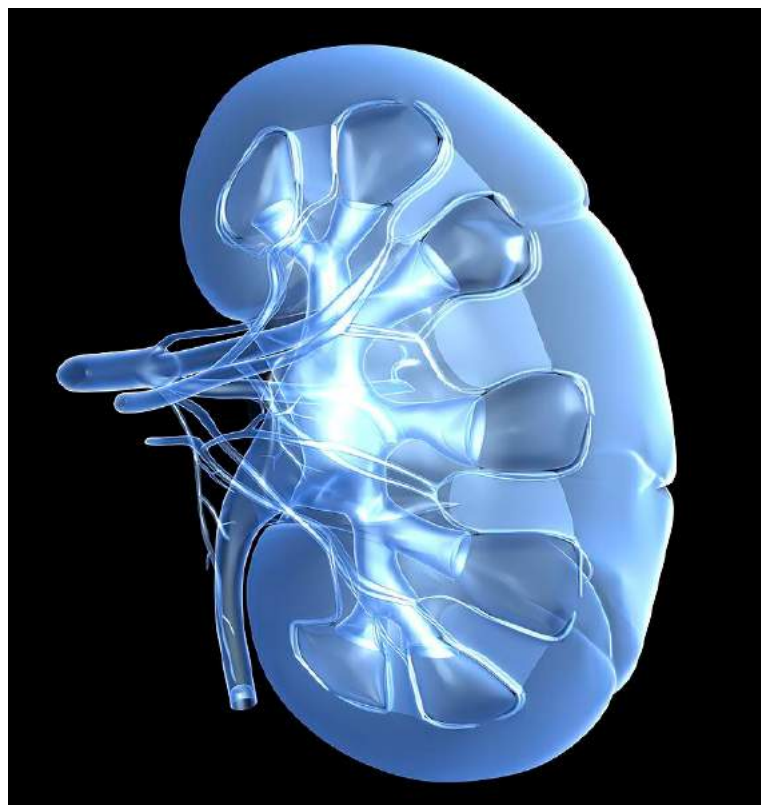
Recipe from Andrea Aquilina, Dietician, The Hospital for Sick Children

Ingredients:

300 g (2/3 lb) boneless grilling steak, ground beef, or leftover roast beef
1 tbsp vegetable oil
1 carrot, peeled and chopped
1 onion, chopped
1 stalk celery, chopped
1 clove garlic, chopped
500 mL (2 cups) low sodium beef broth
375 mL (1 1/2 cups) water
1/4 cup white rice
1 tbsp balsamic vinegar
1 bay leaf
1/2 tsp black pepper

Directions:

Chop meat into bite sized pieces. Heat oil over medium heat in a large pot. Add meat and cook until it is well browned. Add carrot, onion, celery, and garlic. Cook for 5 minutes. Add broth, water, rice, vinegar, bay leaf, and black pepper. Bring to a boil, then reduce to low heat and cook, covered, for 30 minutes.



We want your drawings!

Bring your artwork in at your next visit, and give it to one of the staff in clinic.
We will showcase your art in the next issue of our newsletter.
We can't wait to see your masterpieces!



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MARCH
2016

— KIDNEY —
DISEASE
& CHILDREN

**ACT EARLY
TO PREVENT IT!**

