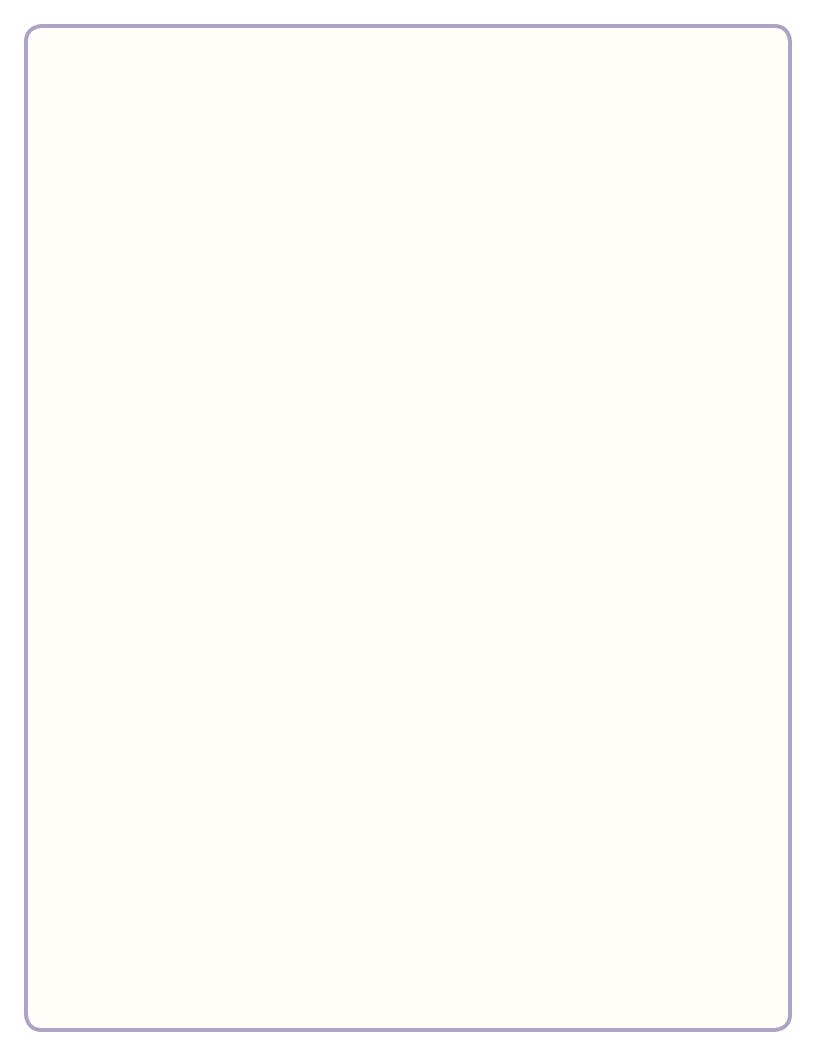
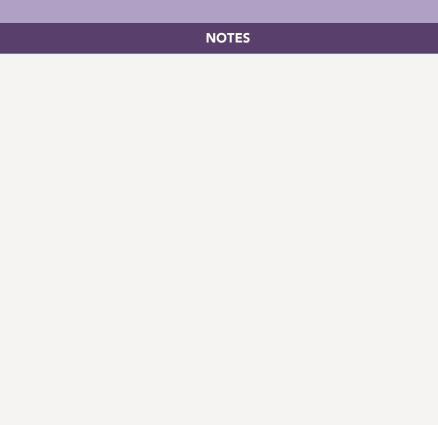


FACILITATOR RESOURCE





RESOURCES MENU

- 1. Your Kidney Health Team
- 2. Meet Your Kidneys!
- 3. Balance
- 4. Connections
- 5. Healthy Eating
- 6. Being Active
- 7. Taking Medicines

8. HEALTHY BLOOD

- 9. Bone Health
- 10. Blood Pressure
- 11. Acid Balance
- 12. Growth
- 13. Chronic Kidney Disease
- 14. Family Coping Resources
- 15. My Coping Resources
- 16. Glossary



8. GLOBAL LEARNING OBJECTIVES

Children and family will be able to list what they need to do to keep their blood healthy and in balance.

KIDNEY HEALTH MODULES DESIGN OVERVIEW

This material was compiled and designed to meet the needs of the diverse children, their families, caregivers and the health care providers who will be facilitating learning about how to live well with chronic kidney disease.

The design incorporates findings from research on providing health education information to children and adults. A number of families agreed to allow the consultant observe their appointments and interview them about learning about and managing their or their child's chronic kidney disease. In addition, health care providers received a questionnaire and were interviewed about their priorities for children and families in order to manage CKD effectively.

To determine initial topic areas, children and families were asked what was most important to know and most important to be able to do to manage their disease well. The Project Team considered what is required to manage CKD well from their perspective. From this information, topics were grouped into the resulting 16 topic areas. Certainly, for parents and children, "being able to do" things to manage CKD took priority over understanding so much about the disease.

Once the topic areas were determined, the consultant worked with pediatric nephrology health care providers to determine learning objectives for the 3 developmental stages and parents and caregivers.

Using plain language principles and best practices for developmental stage learning design, modules were designed to guide learners towards achieving the learning objectives.

Each module begins with an overview of all learning objectives. The learning objectives are informed by the Key Messages and Clinical Targets which are supported by Resource Materials for the facilitator for each module.

Each section of the module begins with reminders about your approach, appropriate for each developmental level. There is ample white space for you to write your own notes and ideas for delivery.

The Parent and Caregiver Resource provides highlights of the concepts and terms for each module as well as the full glossary for that module. There is also a listing of relevant online and library-available resources.

FACILITATING LEARNING

Facilitating learning puts the emphasis on the learners and their interests and abilities rather than on an outside entity. How does this affect what you, as the healthcare provider, do?

- Work with people where they are at.
- If families are not ready to make a change, they do not need to sit through the presentation of materials. You may want to just give the Activity Sheet to these people. Or you may wish to start a conversation about what the Kidney Health Team can do to help the family feel they are ready to make some changes.
- Use Motivational Interviewing techniques.
- Be careful not to ask for more than one change at a time.
- Not everyone will be able to understand or use the information in the same way. You may find yourself revisiting modules with some children and families repeatedly while others will go away and look into things on their own.
- You will be helping people learn how to manage the disease rather than learn about the disease and understand why the doctor or healthcare team is recommending certain types of management.

Connecting and Relating Learning

A key premise of this work is interconnections. As a facilitator, find ways of linking concepts and tools throughout the modules. As much as possible, concepts are built upon throughout the modules. For instance, in Connections we begin to talk about heart health and kidneys. In Blood Pressure, we build upon that knowledge and introduce the concept of perfusion.

Applying information

Encourage children and families to refer back to information and use the concepts and terms presented. Make sure they are holding the "story books" flipping through them and back and forth in a way that makes sense to them. The concepts and information designed are ageappropriate, clinically and medically accurate and meant to be applied. The Activity Sheets are designed for use people at all levels to reinforce vocabulary and concepts.

Visual Learning

The vast majority of people are visual learners rather than auditory learners. Interesting graphics that tell a story are a more effective way for many people to learn than either listening to information on its own or reading dense information. You will notice that the glossary terms are supported through graphics linked to concepts introduced in the modules.

Literacy Levels

In Manitoba, 40% of working adults have low literacy levels. Give people time. Let them contemplate the graphics. Keep your language plain.

RESEARCH KEY FINDINGS

Developmental Stages and Learning Design Key Points

- Importance of play in learning and education for all levels.
- School-age: time to create and reinforce healthy rituals.
- Adolescence: begin to share consequences but limited.
- Delivery of learning is key: recommendation to embrace motivational interviewing as intervention approach.
- Use of transtheoretical / stages of change model.
- HCP as facilitator of learning.

Child / Parent Consultations Summary Key Points

- The "how" needs to come before the "why" in educating. Some patients and families may never get to the "why."
- Global approach to living healthily and move towards the rationale.
- The lived experience is how we need to think about the learning and educating.
- Appreciation for visual cues and teaching aids.
- Need for useable, family-friendly diet information:
 - shopping lists and pantry list.
 - meal plans for breakfasts, lunches, dinners, snacks that are kidney health friendly and will work for whole family.
- Patients and families do and want to learn from each other.
- Value in emailing nurse clinician.

Best Practices for Health Education Summary Key Points

- Emphasis on action-oriented teaching: what people need to do and how to do it.
- Put positive in front of negative: provide hope rather than feed despair.
- Use simple pictures and graphics to display proportions.
- Plain language is not "dumbed down": it is simply clear.

For more information, contact any member of the Kidney Health Advisory Group:

Angela Chotka, MA Julie Strong, BN Tom Blydt-Hansen, MD Diane McKenty, RN

DEVELOPMENTAL LEVEL OBJECTIVES

By the end of this session:

The Pre-School Age Child will be able to:

a) recognize that blood gives you energy

Possible activities include: there is a recipe for strong blood.

a) there is a recipe for strong blood b) the ingredients for that recipe

The Adolescent will be able to identify:

- c) how to check the ingredients
- d) how your body feels if there is too much / not enough of the key ingredients
- e) that s/he has some control over the ingredients through diet, pills and injections
- d) from photos; begin working on a week of balanced meals; plan safely for special occasions; look at eating out menus and make better choices

Possible activities include:

The School Age Child will be able to identify:

- a) there is a recipe for strong blood
- b) the key ingredients of the recipe: iron, vitamins, ESAs and the right amount of blood (blood count)
- c) how to get the ingredients in your body through pills, diet and injections
- d) your kidneys know when you need more blood
- e) we need more blood (ESAs)
- f) we need strong blood (good nutrition)

Possible activities include: a recipe for strong blood with ingredients list;

The Parents and Caregivers will be able to:

- a) understand their role in having foods in home to support strong blood
- b) understand their key role in supervising their child taking medications (adherence)

KEY MESSAGES

1. To Do:

- o healthy diet rich in iron leafy greens, lean red meat helps lower the risk of anemia
- o if medication is needed: first iron supplements then erythrocyte-stimulating medications are added
- o iron supplementation should occur for all anemic infants / children for repletion
- o a multivitamin which includes folic acid is sometimes added, especially with advanced stages of CKD

2. Background Information:

- o monitoring blood tests are the main way of determining if we are reaching healthy targets
- o anemia is progressive: the risk for anemia and need for medications increases with advanced stages of CKD
- o how are the kidneys involved? kidneys make erythropoietin. Erythropoietin stimulates bone marrow to make blood
- o the effectiveness of erythropoietin (endogenous or exogenous) is influenced by the level of uremia, infections and other inflammatory conditions
- o control of anemia is important to maintain a normal energy level; normal neurodevelopment; cardiovascular health
- o poor anemia control can contribute to left ventricular hypertrophy (cardiomyopathy)
- o blood transfusion is rarely needed and is avoided when feasible due to risk of HLA sensitization and possible need for future kidney transplantation
- o anemia can cause specific symptoms and physical signs: fatigue and exercise intolerance
- o anemia can pose risks: developmental delay and heart disease
- o awareness of these signs and symptoms should be individualized to the patient and parents depending on their level of risk

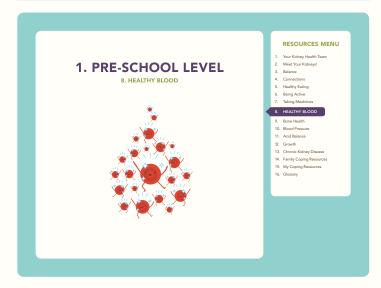
TARGETS FOR FACILITATORS TO BE AWARE OF

- 1. The KDOQI guidelines prescribe specific targets for regulating anemia:
 - o Hemoglobin
 - o Reticulocyte count
 - o Iron
 - o Total iron binding capacity (% iron saturation)
 - o Ferritin

http://www.kidney.org/Professionals/kdoqi/guidelines_anemia/index.htm

- 2. The Dietitian may be consulted to provide additional detail on diet enhancements specific to improving iron intake. These need to be incorporated with other diet restrictions.
- 3. Iron supplements are added in the setting of anemia, to achieve targets that exceed the normal levels of iron status in blood
- 4. Echocardiography is used to identify left ventricular hypertrophy.

PRE-SCHOOL LEARNING



PRE-SCHOOL LEARNING OBJECTIVES

Remember ... children can use words and images to represent objects but are not yet reasoning logically.

The Pre-School Age Child will be able to:

a) recognize that blood gives you energy

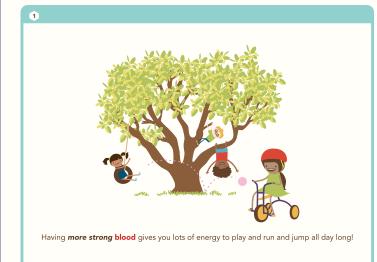
Possible activities include: there is a recipe for strong blood.

MY APPROACH

- 1. Where is this family at? (Stages of Change)
- 2. Acknowledge what children do or say.
- 3. Model attitudes, ways of approaching problems and behaviours towards others rather than telling them.
- 4. Ask questions to provoke thinking; describe pictures.
- 5. Provide hints to assist children when they are struggling with concepts.
- 6. Offer a variety of choices when children are trying to find the answer
- 7. While your time is limited, try to give children and family time to think about the material and messages.

LEARNING SUPPORTS

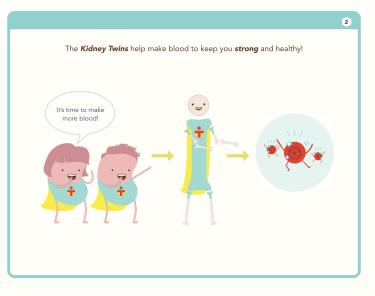
Have you got the Learning Supports you might want to use?



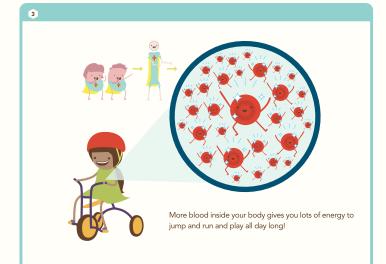
1. What are the children doing?

Yes, they are being active. All these things need lots of energy and having fun. Having enough strong blood gives you energy.

- * Facilitator's Notes: Two key concepts in this module.
 - Enough blood related to message from kidneys
 - Strong blood related to nutrition your body needs

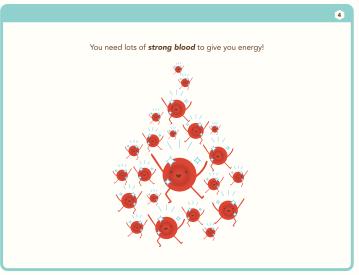


2. The Kidney Twins tell your bones to make more blood so you feel strong and healthy.



3. Why do we want you to have enough blood?

Because having enough strong blood gives you lots and lots of energy!



4. You need lots of strong blood to give you energy!

Review Parent and Caregiver Resource with parents.

UP NEXT: SCHOOL AGE LEVEL

SCHOOL AGE LEARNING



SCHOOL AGE LEARNING OBJECTIVES

Remember ... children can think logically about concrete objects and can apply rules in a consistent way.

The School Age Child will be able to identify:

- a) there is a recipe for strong blood
- b) the key ingredients of the recipe: iron, vitamins, ESAs and the right amount of blood (blood count)
- c) how to get the ingredients in your body through pills, diet and injections
- d) your kidneys know when you need more blood
- e) we need more blood (ESAs)
- f) we need strong blood (good nutrition)

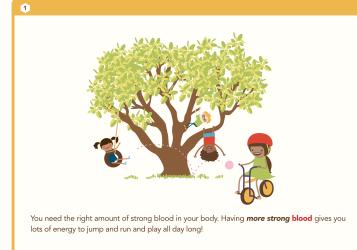
Possible activities include: a recipe for strong blood with ingredients list;

MY APPROACH

- 1. Where is this family at? (Stages of Change)
- 2. Acknowledge what children do or say.
- 3. Model attitudes, ways of approaching problems and behaviours towards others rather than telling them.
- 4. Provide information, directly giving children facts, labels and other information.
- 5. Ask questions to provoke thinking; ask children to describe pictures.
- 6. Provide hints to assist children when they are struggling with concepts.
- Offer a variety of choices when children are trying to find the answer.
- 8. While your time is limited, try to give children and family time to think about the material and messages.

LEARNING SUPPORTS

Have you got the Learning Supports you might want to use?



1. What are the children doing?

Yes, they are being active. All these things need lots of energy. Having enough strong blood gives you energy.

* Facilitator's Notes: Two key concepts in this module. Enough blood related to message from kidneys and strong blood related to nutrition your body needs.



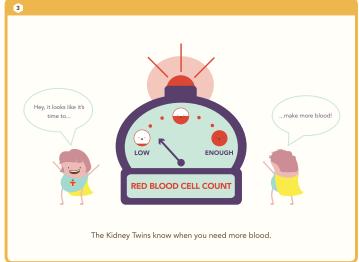
 Do you remember the story about the Kidney Twins? Do you remember what one of their most important jobs is?

They clean the blood.

Now we are going to talk about another really important job the kidneys do: helping your body make more strong blood.

For your blood to be healthy, you need enough of it and it needs to be strong.

* Facilitator's Notes: Two key concepts in this module. Enough blood related to message from kidneys (ESAs) and strong blood related to nutrition your body needs. You might decide to deliver the detail around "enough blood" and "strong blood" in two different sessions depending on developmental level and time.



3. What do you see in this picture? Can you see where there is enough blood?

The Kidney Twins are checking if you have enough blood.

The Kidney Twins know when it is time for your bones to make more blood.

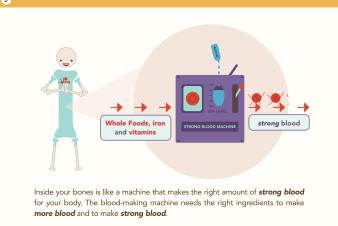
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 - 4. The Kidney Twins send a message to your bones telling them, "it's time to make more strong blood."

Having enough strong blood helps keep you strong and healthy and gives you energy.

The Kidney Twins are helping out again.

Optional Learning if appropriate: The kidneys send a message through ESAs, erythropoiesis stimulating agents.

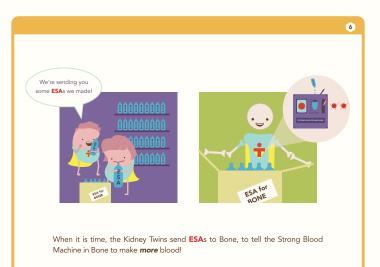
5



5. Your body is like a machine. Inside your bones is like a machine for making blood. Blood is made inside your bones. The kidneys know when it is time for your body to make more blood. We need to put the right ingredients – the right nutrition - inside your body so you have all the blood and all the energy you need.

Can you guess how we get these ingredients inside your body?

We need to eat Whole Foods!



 The kidneys send messages to our bones, saying "make more blood" or "it is enough now; take a rest." These messages are ESAs.

Optional Learning if appropriate: Our kidneys make a hormone called erythropoietin which is a message telling our bones to make more blood.

We need iron, vitamins and a hormone called erythropoietin to make the right amount of blood.

We call the right amount of blood, the blood count.



7. Sometimes, the Kidney Twins need help to send the message to Bone.

We might have to give you ESA medicines. These medicines are an injection.

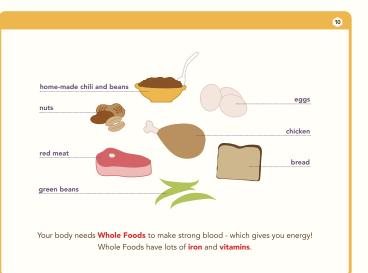
Optional Learning if appropriate: If our kidneys can't make the erythropoietin, we can give you medicines called ESAs. ESAs are erythropoiesis stimulating agents.



8. And, once we get the right parts together, the machine is working well again!



- We have talked about how our body makes enough blood – the Kidney Twins send a message to our bones. Now, we are going to talk about how we get the right ingredients to make strong blood.
 - * Facilitators Notes: Consider delivering the detail around "enough blood" and "strong blood" in two different sessions depending on developmental level and time.

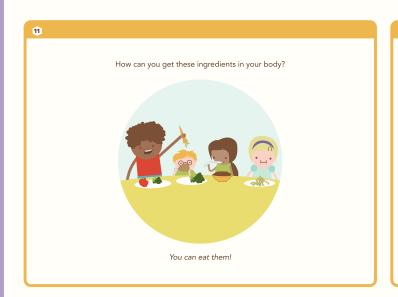


10. Look at this picture. Can you guess what the right ingredients might be?

Your body needs the nutrition from Whole Foods for making strong blood. Let's look at some of the foods we need to make strong blood.

Foods that are high in iron are dark, leafy greens, lean beef, lamb, pork, liver, veal, dark poultry meat, fish.

Also try to eat dark green leafy vegetables, dried peas and beans and fruit. Do you eat some of these foods? Which ones?



11. And, here's an easy question: how do we get these ingredients in our body?

We eat them!

Sometimes your body needs help getting the ingredients inside your body. These can help:

- 12. But, if your body needs help to get these ingredients, we can help:
 - to improve nutrition, you might take supplements
 - to improve iron , you might take iron supplements given as pills
 - to improve vitamin and folic acid intake, there are pills

We test your blood and the tests can tell us if you do not have enough of some ingredients in your blood.



13. What do you see in this picture?

The whole Body Team needs enough strong blood!

Review Parent and Caregiver Resource.

UP NEXT: ADOLESCENT LEVEL

ADOLESCENT LEARNING



ADOLESCENT LEARNING OBJECTIVES

Remember ... many adolescents can reason abstractly and think in hypothetical terms

The Adolescent will be able to identify:

- a) there is a recipe for strong blood
- b) the ingredients for that recipe
- c) how to check the ingredients
- d) how your body feels if there is too much / not enough of the key ingredients
- e) that s/he has some control over the ingredients through diet, pills and injections
- ds from photos; begin working on a week of balanced meals; plan safely for special occasions; look at eating out menus and make better choices

Possible activities include:

MY APPROACH

- 1. Where is this family at? (Stages of Change)
- 2. Acknowledge what the adolescents say and do.
- 3. Model attitudes, ways of approaching problems and behaviours towards others rather than telling them.
- 4. Ask questions to provoke thinking; describe pictures.
- 5. Guide, do not dictate. Youth want info so they can make their own decisions.
- 6. Be patient. Don't be discouraged if your first offers of support are turned down.
- 7. Give opportunities to use strategic thinking, reasoning and problem solving.
- 8. Let them do some evaluation and monitoring of their understanding.
- 9. While your time is limited, try not to give children and family time to think about the material and messages.

LEARNING SUPPORTS

Have you got the Learning Supports you might want to use?



 Having enough strong blood keeps is healthy and gives us energy for all the things we want to do. The kidneys know the right amount of blood we need.

We need enough strong blood so we have the energy to do all the things we want to do – everything from thinking and talking to singing and dancing and boarding and ... *personalize to patient*.

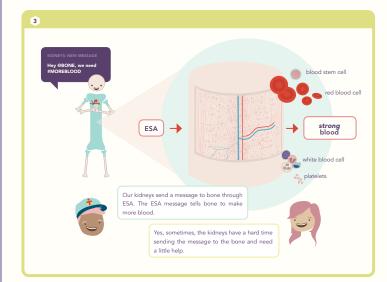
There are certain things we can do to keep our body making enough strong blood so we have the energy for all the things we want to do.

Do you remember we have talked about what the kidneys have to do with blood?



2. Yes, kidneys clean blood.

Today we are going to talk about another very important job when it comes to blood: they help your body make enough strong blood.



 Blood is made inside the bone, in the bone marrow. Kidneys can tell when there is not enough blood, and they send a message using an ESA to bone to tell it to make more blood.

The kidneys are always watching the amount of blood and telling your bone when to make more or when they can stop production.

Optional Learning if appropriate: Our kidneys make a hormone called erythropoietin which is a message telling our bones to make more blood.

We need iron, vitamins and a hormone called erythropoietin to make the right amount of blood.

We call the right amount of blood, the blood count.

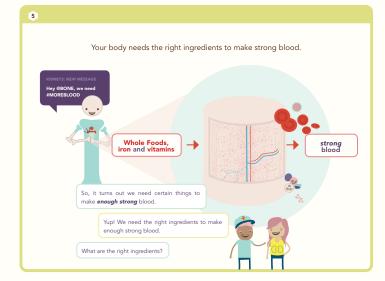


4. Our kidneys make ESAs. Do you remember what ESAs do? They are message to our bone saying "it is time to make more blood."

Sometimes the kidneys have trouble making enough ESAs.

We can test your blood to know if your kidneys are having trouble making the message to send to your bone.

There is a medicine that helps. We can give you an ESA injection.



5. Our body also needs the right ingredients – the right nutrition – to make strong blood. Can you guess how you will get the right nutrition to make strong blood?

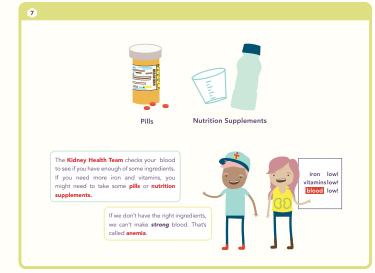
Yes, through eating Whole Foods.



6. Your body really needs foods that are high in iron. Do you know which foods are high in iron?

Foods like dark, leafy greens, dried peas and beans and fruit. Lean beef, wild meats and lamb, pork, liver, veal, dark poultry meat, fish are high in iron.

You can get some iron from fortified cereal, fortified bread and fortified pasta but the meats and vegetables and dried fruits and nuts are better for your body.

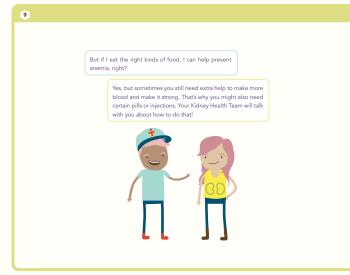


- If we can see through blood tests that you do not have enough of some ingredients in your blood, we can help:
 - to improve nutrition, you might take supplements
 - to improve iron, you might take iron supplements (pills)
 - to improve vitamin and folic acid intake, there are pills

If you don't have enough of the right ingredients, your body can't make strong blood. That is called anemia.



8. Review symptoms of anemia with adolescent. If they have these symptoms, they should let their Kidney Health Team know.



9. There was a lot of information today.

We talked about a recipe for **enough strong** blood.

There are certain ingredients for strong blood. Do you remember any?

• Good nutrition – lots of iron and vitamins.

How do we get good nutrition? Yes, through Whole foods.

It is also important that the kidneys can send the message to your bones. They use ESAs to send this message and sometimes they cannot make enough so we have to give you an injection.

Now you know why we check your blood regularly, right?

Use Activity Sheet and review Parent and Caregiver Resource with parents.











Created by Julie Strong BN, Tom Blydt-Hansen MD, Diane McKenty RN, and Angela Chotka MA with Pediatric Nephrology (Children's Hospital Health Sciences Centre) and Chotka Consulting: Creative Balanced Solutions. With thanks to the Children's Hospital Foundation of Manitoba for their generous support.

For more information about this resource, please contact Pediatric Nephrology at 204-787-4947 or jstrong@exchange.hsc.mb.ca or the Children's Hospital Foundation of Manitoba http://goodbear.mb.ca