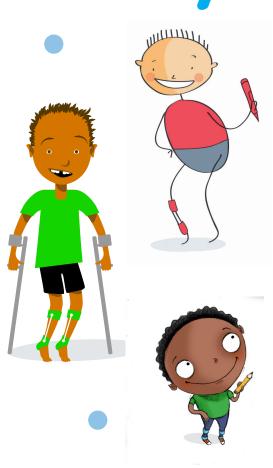
## This is out story An interactive book to use with kids with muscle stiffness of upper and lower limbs









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### **PSEN**

Dysport® (abobotulinumtoxinA) for injection, for intramuscular use 300- and 500-Unit vials.

Dysport is a prescription medicine that is injected into muscles and used to treat increased muscle stiffness in patients 2 years of age and older with upper and lower limb spasticity.

#### **IMPORTANT SAFETY INFORMATION**

#### What is the most important safety information I should know about Dysport?

Dysport may cause serious side effects, including problems breathing or swallowing and/or spread of toxin effects, that can be life threatening and death can happen as a complication. These problems can happen within hours, or days to weeks after an injection of Dysport.

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www.dysport.com/

Please see Important Safety Information throughout and accompanying full Prescribing Information, including Medication Guide with **Important Warning.** 



## IT ALL STARTS HERE!

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OLA

This book will help you do things like:

#### CAPTURE WHAT MAKES YOU UNIQUE

2. LEARN HOW OTHER KIPS LIVE WITH MUSCLE STIFFNESS IN THEIR ARMS OR LEGS (OR BOTH)

3. TALK TO YOUR FAMILY AND POCTORS ABOUT YOUR ARM AND/OR LEG MUSCLE STIFFNESS

L. SET YOUR OWN GOALS

G

Follow the directions on each page. Ask for help from parents, siblings, grandparents or other family or friends when you need it.

# ME AND MY FAMILY

#### I LIVE IN COLUMBUS, OHIO.

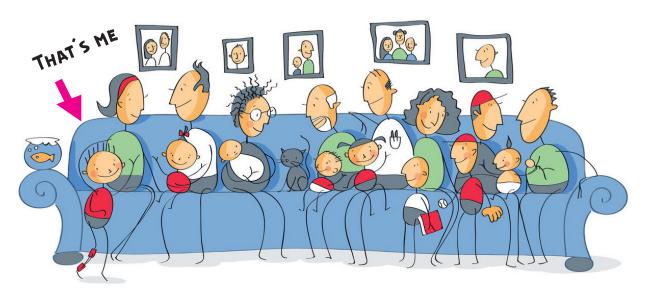
HI! MY NAME IS

I'M 7 (AND A HALF!!)

YEARS OLD.

## I'VE GOT A BIG FAMILY.

THERE'S MY MOM, MY DAD, SPENCER (MY BIG BROTHER). DRAGON (MY PET FISH), 4 GRANDPARENTS, 12 COUSINS, AND A BUNCH OF AUNTS AND UNCLES. I WEAR A BRACE ON MY LEG TO HELP ME BALANCE AND WALK BETTER, JUST LIKE MY AUNT WEARS GLASSES TO HELP HER SEE BETTER!



# YOUR TURN! MY NAME: \_\_\_\_ (Write your name.) AGE I WAS FIRST DIAGNOSED WITH MUSCLE STIFFNESS IN MY ARMS AND/OR LEGS\*: (Write your age in the box.) WHERE I LIVE: (Write your city above. Then draw the shape of your state below in the box.) WHAT I LOOK LIKE AND MY FAMILY: **TURN THE PAGE!** HEREII \*This book is intended for use by children 3 years of age or older.

# WHAT I LOOK LIKE:

(Draw or glue a picture of yourself in the frame below.)



(In the frame below, write names, draw, glue, or tape pictures, to show who's in your family.)

# WHAT I LOVE



# WHAT MAKES YOU HAPPY? ©©

(List 6 things that make you happy and draw a picture next to it. Glue or tape pictures in the right column of more things that make you happy. Color and circle things on Ella's list that you love, too!)



8

# MUSCLE STIFFNESS AND ME

## HI! I'M OLIVER! I'M 5 YEARS OLD!

I HAVE MUSCLE STIFFNESS IN MY ARMS AND LEGS. IT STARTED WHEN I WAS 2 YEARS OLD. (I CAN'T REALLY REMEMBER, BUT THAT'S WHAT MY DAD SAYS.)

#### WHEN MY MUSCLES GET **STIFF,** THEY FEEL TIGHT AND CRAMPY. NO FUN!;(

DIFFERENT THINGS HELP. SOMETIMES MY **MOM** RUBS MY STIFF MUSCLES. SOMETIMES I STRETCH OR EXERCISE. SOMETIMES I GO TO OT OR PT. SOMETIMES I GET MY DYSPORT INJECTIONS. AND SOMETIMES I WRAP MYSELF IN MY SUPER SOFT KOALA BLANKET AND WATCH VIDEOS ON THE SOFA.

HERE'S WHERE

MY

GET

STIFF

MUSCLES

Ever since Oliver started getting Dysport injections, he gets relief from his muscle stiffness for about 6 months. That means more time doing the things he loves! We know it may be time for another injection when Oliver's muscles don't respond as well or his braces start to feel awkward. —Oliver's Dad

#### **IMPORTANT SAFETY INFORMATION**

#### What is the most important safety information I should know about Dysport? (continued)

• **Problems swallowing, breathing, or speaking.** Treatment with Dysport can result in swallowing or breathing problems. People with pre-existing swallowing or breathing problems may be at greater risk following treatment with Dysport. Swallowing problems may last for several weeks; you may need a feeding tube to receive food or water. If swallowing problems are severe, food or liquids may go into your lungs.

Please see Important Safety Information throughout and accompanying full Prescribing Information, including Medication Guide with **Important Warning.** OT=occupational therapy; PT=physical therapy.



## WHERE IN YOUR ARMS AND/OR LEGS DO YOUR MUSCLES FEEL DIFFERENT?

(Circle or draw an arrow.)

WHAT DO YOUR MUSCLES FEEL LIKE?

(Check Vas many as you want.)

Stiff 🗆

Other 🗆

**NOW TURN THE PAGE!** 

(Describe in your own words.)

Tight 🗆

(What does your hair look like?)

(What do your clothes look like?)

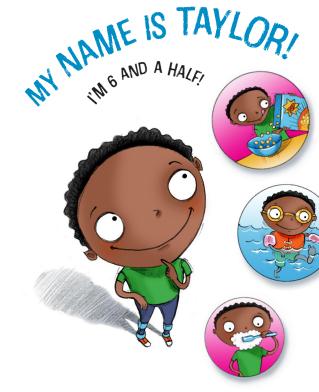
Crampy

G0!

THINGS THAT HELP WHEN YOUR	
MUSCLES FEEL STIFF:	(Now, draw 4 of the items from your list!)
(Circle as many as you want.) (Add your own.)	
МҮ МОМ	
MY DAD	
MY BROTHER / SISTER	
MY TEACHERS	
MY FRIENDS	
OT / PT	
MY PET	
MASSAGES	
EXERCISING	
STRETCHING	
HEATING PADS	
WARM BATHS	
LISTENING TO MUSIC	
MY DOCTOR	
MY SUPPORT DEVICE	
MY STRETCHING BRACE	

OT=occupational therapy; PT=physical therapy.

# WHAT I WANT TO LEARN TO DO

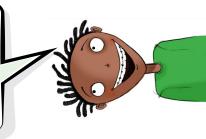


Since I started getting my Dysport injections, the muscle stiffness in my arms has gotten better. With looser muscles, I learned to zip my own jacket. Yes! My mom always reminds me that if I have a hard time swallowing, breathing, or speaking, or have any other side effects that I should let her know right away.

There are still sooooooo many other things I want to learn, like how to:

Pour my own cereal in the morning Swim with my big brother Brush my own teeth (My Mom made me add that one! Hahaha!)

Since Taylor started getting his Dysport injections, he can keep up with me better when we play. He does have to wear his safety gear when we swim, so we play games together in the shallow end of the pool. —Taylor's Big Brother



#### IMPORTANT SAFETY INFORMATION

#### What is the most important safety information I should know about Dysport? (continued)

• Spread of toxin effects. The effects of botulinum toxin may affect areas of the body away from the injection site and cause symptoms of a serious condition called botulism which include: loss of strength and muscle weakness all over the body, double or blurred vision, and drooping eyelids, hoarseness or change or loss of voice, trouble saying words clearly, loss of bladder control, and trouble breathing or swallowing. The risk of these symptoms is probably greatest in children treated for spasticity. These problems could make it unsafe for you to drive a car, operate machinery, or do other dangerous activities.

Please see Important Safety Information throughout and accompanying full Prescribing Information, including Medication Guide with **Important Warning.** 

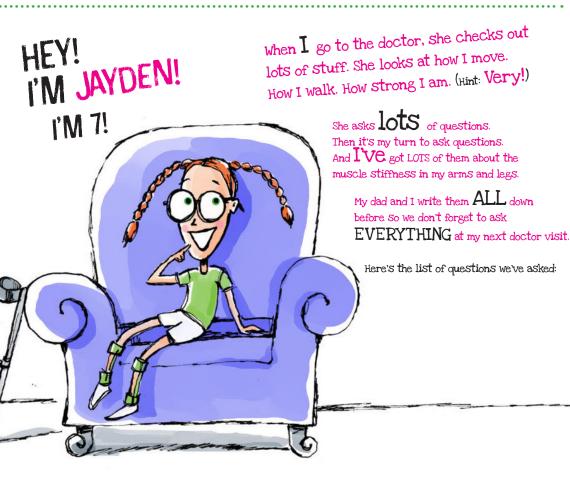


## Make a collage of stuff you want



(Grab old magazines with lots of pictures and some glue or tape. Tear or cut out stuff you want to learn. Ask a parent or sibling to help. Ask them to add some pictures, too!)

# VISITING THE DOCTOR



#### **IMPORTANT SAFETY INFORMATION**

#### What is the most important safety information I should know about Dysport? (continued)

Call your doctor or get medical help right away if you experience these problems after treatment with Dysport.

**Do not receive a Dysport injection if:** you are allergic to Dysport or any of its ingredients, or cow's milk protein; you had an allergic reaction to any other botulinum toxin product, such as Myobloc<sup>®</sup>, Botox<sup>®</sup>, or Xeomin<sup>®</sup>; or you have a skin infection at the planned injection site.

Please see Important Safety Information throughout and accompanying full Prescribing Information, including Medication Guide with **Important Warning.** 



Why do I have muscle stiffness? What can we do to help my muscles feel less stiff? Can I get better at braiding hair? Can I learn to ride a scooter? How do Dysport injections help? Will injections hurt? Who can come with me to my injection appointments? How soon can I eat after injections? What about before my injections? Can I go swimming after I get my injections? My dad has questions, too. Is an injection the same thing as a shot? What results can we expect with **Dysport injections?** How long do results typically last? When do we schedule a follow-up appointment? What is the injection experience like? What side effects should we be aware of with Dysport?

Is there financial assistance to help us pay for Dysport injections?\*

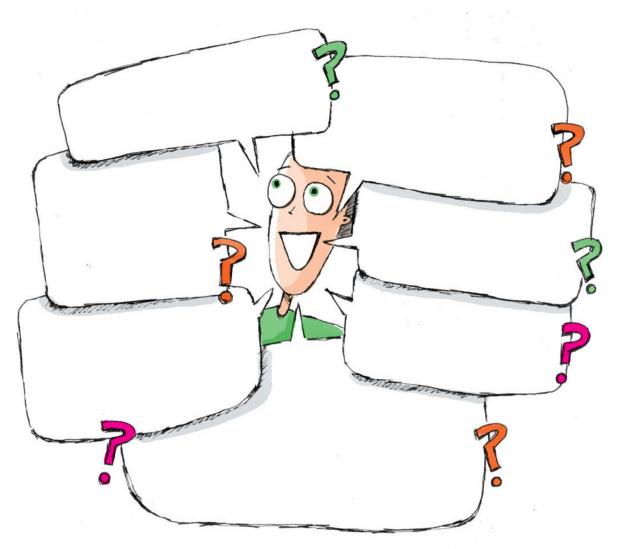
What treatment goals should I set for Jayden?

\*Patients are not eligible for copay assistance if they are enrolled in any state or federally funded programs for which drug prescriptions or coverage could be paid in part or in full, including, but not limited to, Medicare Part B, Medicare Part D, Medicaid, Medigap, VA, DoD, or TRICARE, or where prohibited by law. Other terms and conditions apply.





(Write your questions in the bubbles.)



# What for a cost of the second of the second

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#### Help Amy get to the milkshake! **INJECTION DAY** (Get a green cravon and trace the path to the milkshake!) I'm Amy I'm 7! I get a good night's sleep I pack a backpack before my injection appointment. with games, puzzles, In the morning I eat breakfast as and books (like this one!) long as my doctor says it's okay. GETTING INJECTIONS IS NO FUN I bring my favorite BUT I DO LIKE HOW MY MUSCLES stuffed animal (Bear!) FEEL AFTER MY INJECTION (MY MOM SAYS to keep me company. THAT SOMETIMES, APPOINTMENT- WAY LESS STIFF. I'M TOO HONEST. WHATEVER THAT MEANS.) 12 I'VE BEEN GETTING INJECTIONS FOR A WHILE NOW AND THIS IS HOW IT WORKS FOR ME: When my arm or leg START HERE!! muscles get stiff I tell my mom right away. MILKSHAKE TIME!! YUM Once they make sure I'm not sick, it's injection time. We tell my teachers I'll be out of school that day, and my mom My mom makes an takes off work. appointment to see SCHOOL 1 if I need another se of injections.

#### **IMPORTANT SAFETY INFORMATION**

#### Before you receive a Dysport injection tell your doctor:

• About all your medical conditions, including if you have a disease that affects your muscles and nerves (such as ALS or Lou Gehrig's disease [amyotrophic lateral sclerosis], myasthenia gravis, or Lambert-Eaton syndrome). You may be at increased risk of serious side effects, including difficulty swallowing or breathing.

Please see Important Safety Information throughout and accompanying full Prescribing Information, including Medication Guide with **Important Warning.** 



The doctors and nurses do everything they can to make the injections as easy as possible.

Having a regular plan for injection day reduces stress and makes the day run as smoothly as possible. It's also helpful that Amy now knows what to expect after the injections, like soreness at the injection site. —Amy's mom



# TRACKING MY PROGRESS

## **MY NAME IS DREW!**

I'M 5. My dad helps me do lots of things like get dressed.



He also helps me keep track of how I feel after my injections. we tell my doctor this stuff at our next visit.

> The doctor says it helps her make the best choices about my injections.

That way, I can do more of the stuff I like to do!



#### **IMPORTANT SAFETY INFORMATION**

Before you receive a Dysport injection tell your doctor (continued):

• If you have or have had any of the following: a side effect from any botulinum toxin in the past; problems with breathing such as asthma or emphysema; swallowing; bleeding; diabetes; and slow heartbeat, or problems with your heart rate or rhythm.

Please see Important Safety Information throughout and accompanying full Prescribing Information, including Medication Guide with Important Warning.



# Drew's Tracker.



#### HOW DOES DREW FEEL AFTER HIS DYSPORT INJECTIONS?

- (Sometimes a runny nose or slight fever.)
- Other common side effects of Dysport that we look out for are
- upper respiratory infection, stuffy nose, sore throat, and cough.
- Our doctor also reminds us at each visit of potential serious side
- effects including problems breathing or swallowing.

#### How soon did we see reduction in muscle stiffness?

(Usually, muscles are most loose about a month after injections.)

#### Has his ability to do everyday tasks improved?

(For some things, yes. For others, no. But in general, the injectionsalong with all the other things like OT, PT, and practicing new skills—definitely help.)

#### How is Drew's progress?

(We usually see the doctor about 6 to 8 weeks post injection

to evaluate how well his most recent injections are working.)



Give this book to your mom, dad, grandma, grandpa, or another adult to track your OWN progress: (Circle answers.)

# My Tracker

J	(en cre	one)	5,710	e my i	njec n	713,			/		E / SAN
Can you mo	ve bett	er? (	Circl	2)					•	YES	NO
How many u	veeks af	ter	your	inject	ion ap	point	tmen	t did	you	start	to feel
less muscle	stiffne	ss —	like y	you co	old ma	ove b	ette	r, or	felt I	more l	oose?
(Circle)	1	2	3	4	5	6					
	-		-	-	-	-					
Did you have	e any of	`the	se	UPP	ER RE	SPIR		RY IN	IFEC	TION	
side effects?* (Circle) <b>SORE THROAT</b>											
				STU	FFY O	RRL	JNN	Y NO	SE		
				COL							
				FEV							
Can you do	more th	ings	you i	want :	to do?	(Ci	ircle)		•	YES	NO
How many months after your last injections did your											
muscle stiff	ness co	me b	ack?	(Cir	cle)	1	2	3	4	5	6

\*Tell your doctor if you have any side effect that bothers you or that does not go away. These are not all the possible side effects of Dysport. For more information, ask your doctor or pharmacist. You may report side effects to the FDA at **www.fda.gov/medwatch or call 1-800-FDA-1088.** 

## Notes & Goal Tracker

Use the blank pages at the back of the book for you and your family to take notes and track your progress :)

Remember, you can change your goals any time you want!

# GOAL ACHIEVED!





#### **IMPORTANT SAFETY INFORMATION**

Before you receive a Dysport injection tell your doctor (continued):

• If you have plans to have surgery, had surgery on your face, have weakness of your forehead muscles (trouble raising your eyebrows), drooping eyelids, or any other change in the way your face normally looks.

Please see Important Safety Information throughout and accompanying full Prescribing Information, including Medication Guide with **Important Warning.** 







We are so pleased with how Jordan is doing on Dysport injections. Even though he does things a little different than his friends, he's able to achieve similar milestones! —Jordan's Mom

# EXTRA STUFF

(You and an adult can use this page to write down anything you want, like questions for your doctor.)

## NOTES

(You and an adult can use this page to write down your short-term and long-term goals. Revisit this page often to track your progress. Check the box when you accomplish a goal.)

......

## GOALS

-		
_		

# EXTRA STUFF

## NOTES FROM MY DOCTOR

#### **IMPORTANT SAFETY INFORMATION**

#### Before you receive a Dysport injection tell your doctor (continued):

- If you are pregnant or breastfeeding or plan to become pregnant or breastfeed. It is not known if Dysport can harm your unborn baby or if it passes into breast milk.
- About all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal products. Using Dysport with certain other medicines may cause serious side effects. Do not start any new medicines until you have told your doctor that you have received Dysport in the past.

**Especially tell your doctor if you have received** any other injections of botulinum toxin in the last four months or ever; Myobloc<sup>®</sup>, Botox<sup>®</sup>, or Xeomin<sup>®</sup> (exactly which ones); an antibiotic recently by injection; or if you take muscle relaxants; allergy, cold or sleep medicine.

#### Most Common Side effects of Dysport in:

adults with lower limb spasticity include: fall, muscle weakness, pain in your arms or legs.

adults with upper limb spasticity include: muscle weakness.

children (2 to 17 years of age) with upper limb spasticity include: upper respiratory infection and sore throat.

children (2 to 17 years of age) with lower limb spasticity include: upper respiratory infection, stuffy or runny nose and sore throat, cough, and fever.

adults with cervical dystonia include: muscle weakness, difficulty swallowing, dry mouth, injection site discomfort, tiredness, headache, muscle pain, problems speaking, injection site pain and eye problems.

Tell your doctor if you have any side effect that bothers you or that does not go away. These are not all the possible side effects of Dysport. For more information, ask your doctor or pharmacist. You may report side effects to the FDA at www.fda.gov/medwatch or call 1-800-FDA-1088.

Please see Important Safety Information throughout and accompanying full Prescribing Information, including Medication Guide with **Important Warning.** 

## This Book belongs to:

(Write child's name below.)

## Care team contact info:

(Write the names and phone numbers of child's care team members.)