NDRF Youth Network
Fainting Robins Newsletter
“The Young and the Dizzy”

Spring/Summer 2001

About being Young and Dizzy
Overview of Dysautonomia:

By: Dr. Julian Stewart

Circulatory integrity is necessary for us to go about the tasks of daily life. Circulatory abnormalcy becomes evident whenever our cardiovascular system is stressed. There are two basic daily stressors of the cardiovascular system: standing upright and exercise. An inability to remain upright depends more on the circulation than the heart and therefore circumstances which interfere with circulatory function are often most evident during standing up (AKA Orthostasis). Thus, many of these illnesses that we deal with are grouped together as a form of **“orthostatic intolerance”**.

The autonomic nervous system is an important enabler of orthostasis although not the only mechanism for this. Thus should there be **“autonomic dysfunction”** related to the circulatory system, it is likely that the ability to maintain upright stance will be impaired. However, it is true that the autonomic nervous system controls more than circulation and may impact also on gastrointestinal, pupillary, genitourinary, temperature regulation and endocrine systems (in fact all human tissues). It is also true that other mechanisms contribute to circulatory and orthostatic tolerance including blood volume, regulated largely by the kidneys, as well as immune systems, endocrine systems, structural properties of blood vessels and muscle and so forth.

The word **“Syncope”** translates from the Greek as “a cutting short” and is defined as a sudden short-lived loss of consciousness and ability to maintain posture caused by impaired blood flow to the central nervous system. The brain blood flow is simply inadequate to sustain consciousness. Approximately 90% of syncope in children is either “neurocardiogenic” or “unexplained”. Often the unexplained variety is reclassified as neurocardiogenic once tilt table testing has been performed. **Neurocardiogenic Syncope** is the current term for fainting mediated through a combination of inappropriate blood vessel and heart rate control. It is rarely fatal but it can be injurious. Synonyms for Neurocardiogenic Syncope include Neurally Mediated Syncope and Vasovagal Syncope. Almost all of Neurocardiogenic Syncope in children is Vasovagal. Vasovagal Syncope almost always occurs in the upright position, which may include sitting.

(continued)

Many syncopal patients are well between faints. However, chronic orthostatic intolerance also occurs. Patients with **Chronic Orthostatic Intolerance** are chronically ill. Symptoms of chronic orthostatic intolerance include dizziness, altered vision (blurred, “white outs”, “black-outs”), fatigue, nausea, and palpitations. A large fraction of patients also experience headaches, tremulousness, difficulty breathing or swallowing, sweating, pallor, and other vasomotor symptoms.

Postural Orthostatic Tachycardia Syndrome is a disabling disease state and is the most common reason for referral for orthostatic intolerance in adults. It is an emerging form of orthostatic intolerance in children. Patients have day-to-day disability - a feature not shared with those with simple faint. These patients are often unable to hold jobs or attend schools. Our understanding of its pathophysiology remains incomplete. The central physical finding is upright tachycardia although hypotension and resting tachycardia may also be present. Hypotension may follow or occur with tachycardia. Onset of symptoms often follows an infectious disease and may be related to inflammatory mediators. Patients with this syndrome display an unusual amount of pooling in the lower extremities often associated with acrocyanosis. There are a number of explanations for abnormal venous pooling including impaired veins, a selective autonomic impairment that affects the lower extremities, changes in neurotransmitter receptors, leaky capillaries, an aberrant gene for the norepinephrine reuptake transporter protein producing alternations between hypertension and hypotension in the same patient dependent on norepinephrine stores, and defects in the release of norepinephrine, the neurotransmitter most responsible for blood vessel contractile ability. Such results point to the likelihood of different types of vascular abnormalities resulting in a common pathway of postural tachycardia associated with symptoms of orthostatic intolerance.

Treatment plans must be individualized. Besides pharmaceutical measures prescribed by your doctors, there are some simple maneuvers that are often helpful. These include lying down, leg crossing, curling toes, bending at the waist, and squatting. Increased fluid and salt intake is always helpful in improving blood volume. Lower body exercise, particularly isometric exercise, can be of genuine help.

Julian M. Stewart, M.D., Ph.D
The Center for Pediatric Hypotension
New York Medical College
www.syncope.org

Symptoms of these conditions may include:

Excessive Fatigue
Exercise Intolerance
Recurrent Syncope or Near Syncope
Dizziness
Nausea
Tachycardia
Palpations
Visual Disturbances
Tremulousness
Weakness
Chest Discomfort
Shortness of Breath
Mood Swings
Migraines
Gastrointestinal Problems
Noise/light sensitivity
Insomnia
Brain Fog
Hypotension

High School Graduations

The NDRF Youth Network would like to congratulate **Graduating High School Seniors, Jenni Hinman** and **Kim Wing**! We all know that you worked hard to get to this point and we wish you the very best! This fall Jenni will be attending Ohio State University and majoring in Pre Medicine! She wants to become a Child Psychiatrist! Kim will be attending College of Charleston and majoring in Pre Medicine too! She wants to be a Pediatric Neurologist! Talk about turning your experience into something positive! **Go for it girls!**

Yesterday

By: Jenni Hinman
Age 17, Ohio

When boys meant "Yuck"
and friends were new
Dreams were unshattered
and worries were few

When recess was too short
and life too long
Decisions came easy
Without the need to belong

When storks delivered babies
and passions weren't so strong
Friendships were unbroken
Right was right, wrong was wrong

When bad things didn't happen
When only skinned knees brought tears
and the night light in it's socket
quieted all your fears

When farewell meant only for summer
and real friends didn't part
The fun went on forever
and never left a broken heart.

What POTS Feels Like

By: Kim Wing
Age 17, South Carolina

Sometimes...

*You feel so dizzy that you can't stand.
*The room is spinning so fast that you fall down if you try to stand.
*The pressure on your chest is so heavy that you can't breathe.
*Your tachycardia is so fast that you think your heart is going to explode.
*Your so fatigued that just opening your eyes seems like a chore.
*You lose things...even friends.
*Insomnia isn't a good enough word for it.
*Your headaches are so bad that even the refrigerator humming hurts.
*Your blood pressure suddenly "hits the roof" and gives you a horrible headache.
*Your blood pressure suddenly "bottoms out" and makes you pass out or wish you could pass out.
*You can't concentrate...it hurts to think.
*You get numb feelings in your hands, feet arms, and legs that feel like 1000 needles sticking you.
*You turn a pretty blue color.
*You get so pale that your almost translucent.
*Your chest pains feel like your being stabbed.
*You forget.
*Just talking hurts.
*Your eyes dilate and light hurts them.
*You feel like there is a "tennis match" going on inside your head.
*Noise gets so bad that your heart beats hurt.
*People gossip.
*Your alone.

I Am A Teenage Dysautomanic!

By: Kim Wing
Age 17, South Carolina

When I was in 7th grade I was a National Champion Cheerleader and had all the friends that a girl could ask for. I had it made - or so I thought! It never dawned on me that one day I would not even be able to stand - let alone cheer for my school team! I started passing out 7-8 times a day. No one knew why. At first everyone brushed it off and thought that I must have diabetes or low iron levels or something. My Mom took me to our family doctor and he did lab work and the tests were all negative. He did notice that my heart rate was very high. He sent me to a Pediatric Cardiologist. They put me on heart monitors and ran tests and basically everything still came out fine. I had the doctors baffled. Then they did a tilt table test on me. All I wanted at that point was to go back to school, be with my friends, and go back to Cheerleading. Naive! During the tilt I passed out within 2 minutes and my heart stopped for 10 seconds. They narrowed it down and said that I had "autonomic dysfunction." By 8th grade I was still passing out 5-6 times a day and I had most of the other terrible symptoms of POTS (dizzy, noise/light sensitivity, brain fog, mood swings, fatigue, exercise intolerance, nausea, chest pain, weakness, migraines etc.) and the school said "Enough!" and put me on Homebound Teaching. This broke my heart. Worst of all they would not let me do Cheerleading anymore. I thought my world was coming to an end! I found out that I didn't have the true friends that I thought I had. My whole life changed overnight. My friends went on without me and never looked back. After research we found Dr. Phillip Low, who specializes in Autonomic Dysfunction at Mayo Clinic. We drove all the way from South Carolina to Minnesota to see this doctor. He ran test after test on me and I felt like a lab rat. He diagnosed me with POTS and put me on medications, salt and fluids. It was not easy! It took lots of hard work and we had to adjust my medications and I had to adjust my lifestyle. I never thought I would be able to say this but I am fine now! I have not passed out in a year and my POTS symptoms are much, much better! I am getting on with my life and I have new and better friends now. I am a different person...a new improved version of my former self. So for those of you who think that you will never get better...think again! Look at me! I am living proof that you will get better! It's a long road but you will get there! If you want to talk to someone who understands what you are going through...I am a member of the NDRF Youth Network and my name is Kim (you can get my email address through the Youth Network Membership). And if you're a friend of someone impacted with Autonomic Dysfunction - please stick by them and you may learn something about true friendships!

True friendship is like sound health.
The value of it is seldom known until it is lost.
Charles Caleb Colton

The NDRF Youth Members wish to sincerely thank our parents, siblings, supportive teachers, and true friends for all they have done to help us through our rough times. Many thanks to those who continue to support us and to Dan and Linda Smith for allowing us to stand counted! A special thanks to Angela Dowd and Terry Fath for their time, talent, and generous support towards our membership cards. *THANK YOU!*

Letter Writing Angels

We would also like to sincerely thank Mrs. Moody's 5th Grade class at T.C. Martin Elementary School in Hughesville, MD for taking the time to write some of our Youth Network members. This letter writing venture started out quite innocently with their request to write someone who could use a letter and/or cheering up and they have now written several of our members. Your letters have brightened many lives and you have made a difference to us! Thank you for showing the true spirit of giving!

Giving Back

Have you ever wished that you could find a way to help a child that is suffering? I am 11 years old and have CFS and POTS. I know that it means a lot to me when people go out of their way to do something nice to brighten my day. So I wanted to do the same thing for someone else. I donated my hair to Locks of Love. Last September I had 12 inches cut off and sent it to Locks of Love. Because of this 3 other kids in my community have now donated their hair too. It is really neat to think that lots of kids will be helped now. Knowing that I helped someone else makes me feel really good about myself.

Megan Robinson
Age 11, New York

Across the Ocean

Congratulations to all of you - getting your own NDRF Youth Network and Newsletter! I live in England. 8 years ago my daughter, Francesca, was diagnosed with Reflex Anoxic Seizures (RAS). To make a long and difficult story short, Francesca was diagnosed "eventually" after having these "weird" attacks. I was so relieved to know "what" she had, but I felt so **ALONE** because no one had ever heard of it. I run a RAS support group here in the UK. I attended the NDRF Conference in July 2000 and I met Linda and Dan Smith and Dr. Blair Grubb. It is evident that the children themselves want to be able to talk and exchange views. We have a STARS Newsletter too and it is open to everyone. We also publish many information leaflets regarding RAS. Should you need any copies or wish to be added to our mailing list, please feel free to contact me. Just so you know: One of the first things I learned was that children with RAS have average to **ABOVE** average intelligence! My first thought was "Great, I'd rather Francesca be below average and not have the attacks!" Now, I can see that she is just the same as the other children except she has something special - she has RAS - and that is what makes her the person she is and I wouldn't change that for the world! I love her for what and who she is! I hope we can work together ACROSS THE OCEAN!

Dizzy Dysautomaniac's

Those impacted with Dysautonomia often experience dizziness, brain fog, and clumsiness due to the lack of oxygen getting to the brain. These symptoms can come on very suddenly which makes for some very traumatic moments and even some laughable moments. The NDRF Youth Network kids try to laugh about some of their more graceful or memorable "dizzy moments." Although we in no way make light of these conditions, as we struggle with very traumatic symptoms on a daily basis, we do try to find some humor in our situations when we can.

In honor of "dizzy dysautomniac's" everywhere we wanted to share some jokes with you. Linda Smith, Executive Director of the NDRF, is a blonde with Dysautonomia, and the kids wish to dedicate these jokes to her. Thank you Linda for teaching us that we can laugh at ourselves.

*** Question:** How do you make a blonde <u>without</u> Dysautonomia faint?
***Answer:** You put a scratch and sniff sticker at the bottom of a swimming pool!

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One day a blonde with Dysautonomia was putting a puzzle together. She was really stumped, and the pieces were just not fitting together. She finally asked her husband to help her. She said, "This puzzle is supposed to be a Tiger will you help me put it together?" He looked over at what she was doing, rolled his eyes, and said "Honey, put the Frosted Flakes back in the box!"

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You Know you have Dysautonomia if:

When your doctor asks you if your allergic to anything and you can say "GRAVITY!"

When your brain re-dials as much as your Internet connection does!

When your perfectly fine one minute and then the next thing you know your flat on the floor looking up and your friends are all standing over you with dumb looks on their faces saying "Hey, man...WHASSUP!" And you know it's sure not you!

FAMILY CAREGIVING “I’m a Kid! – How can I be a CAREGIVER?”

When I was asked to write a little column for this newsletter, I knew exactly what I wanted to talk about – the “**other**” kids. Who are the other kids? The other kids are the sisters and brothers and sons and daughters, of people who have dysautonomia. **Yeah! The people who are affected by the illness – and live it everyday – but don’t really have it.** What do I mean? Well, if any of you have parents caring for your grandparents or your grandparents taking care of great grandparents, or other loved ones, you know that they are called “**caregivers**.” **Family caregivers**, not doctors or nurses, but people like you and me who have to help with, or worry about, someone we love. And sometimes, because of their illness, there are things we healthy people can’t do. Like the times when Mom can’t drive you to soccer, or when you have to miss out on something because your sister is just too sick. It just seems like nobody really understands what you’re feeling or going through and suddenly you have to take the “back seat.”

Sometimes you just want to scream! You may ask, “Why is this happening to me?” “Why do I have to have a sick person in the family?” “What am I supposed to do?” And yes, sometimes you may even feel guilty for being the healthy one. Just because we love someone doesn’t mean we know how to deal with all this. Remember, this isn’t the flu and chicken soup and three days of bed isn’t going to make it go away! But, guess what? You’re not alone. So many people have the same reaction; not just for dysautonomia, but also for all kinds of problems; medical, emotional, physical, you name it. It’s not easy to be a caregiver, and an illness like this in the family affects <u>everyone</u> in the family. With dysautonomia it is tougher than with most conditions. <u>You</u> know something’s wrong, but they look so healthy! <u>You</u> know something’s wrong, but the doctor can’t always find it! <u>You</u> know something’s wrong but school and friends can’t see it. And they change from one minute to the next! It’s tough – that’s part of being a caregiver.

Caregivers are very special people and we know a lot about what affects them; and what they are going through. We can’t change what’s happening to the person with dysautonomia – that’s for doctors and researchers – but we can do a lot to help <u>you</u> and other members of your family who are the caregivers. Being a caregiver isn’t easy and with long-term illnesses like dysautonomia you need to be prepared for the future so that you feel better. **We help caregivers – young and old.** We have learned neat little things that we can help you with that can improve your situation. We have helpful hints on all kinds of things that you never thought about…but that can make a big difference.

You can e-mail your questions and concerns, and maybe even schedule a one-on-one chat with a professional who knows and cares what you’re going through. We are not going to solve all your caregiving problems at once, but it’s a great start and **you** deserve it!

E-mail your questions and concerns in strictest privacy to YouthCordNDRF@aol.com. They will get to me and we will take it from there. Show this to other members of your family – everyone can benefit from knowing a little more.

David Levy, JD, President, Family Caregiving, Inc.

Are you a carrot, an egg or a coffee bean?

Contributed by: Michael Steel
Age 15, Colorado

A daughter complained to her father about her life and how things were so hard for her. She did not know how she was going to make it and she just wanted to give up. She was tired of struggling. It seemed like as soon as one problem was solved, a new one arose.

Her father, a Chef, took her into their kitchen. He filled three pots with water and placed each pot on a high fire. Soon the pots all came to a boil. In one pot he placed carrots, in another he placed eggs, and in the last one he placed ground coffee beans. He let them continue at a steady boil, without saying a word. The daughter impatiently waited, wondering what he was doing. In about twenty minutes he turned off the burners. He fished out the carrots and placed them in a bowl. He pulled out the eggs and placed them in a bowl. Then he ladled the coffee out and placed it in a bowl.

Turning to his daughter he said, “What do you see?” “Carrots, eggs, and coffee,” she replied. He brought her closer and asked her to feel the carrots. She noted that they were soft. He then asked her to take an egg and break it. After pulling off the shell she observed the hard-boiled egg. Finally, he asked her to sip the coffee. She smiled as she tasted its rich flavor and inhaled its deep aroma. She asked, “So what is all this about, Dad?”

He explained that each of the items had faced the same adversity, boiling water. But each reacted differently. The carrot went in strong, hard, and unrelenting. But after being subjected to the boiling water, it softened and became weak. The egg had been fragile. It’s thin outer shell had protected its liquid interior. But after sitting through the boiling water, the inside became hardened. The ground coffee beans were unique however. After they were in the boiling water, they had changed the water!

Which are you? He asked his daughter. “When adversity knocks at your door how do you respond? Are you a carrot, an egg, or a coffee bean?

* * *

Being Alone

By: Susie Hetrick
Age 15, Ohio

I never thought that I would ever have a major illness. I was always healthy. I got sick in 1998 with sinus infections and bronchitis, and then headaches, dizziness, and blurred vision. Everyone thought I was faking, but I thought I was going insane because every test the doctor's did came out negative.

My friends stayed their distance from me; maybe they were afraid they would catch it. I passed my time staying in a dark room with hardly any noise. Maybe a little music...but not much. Noise got to me.

I was alone.

In my 9th grade year I got teased a lot because I missed so much school. I didn't feel like I belonged anymore. People seemed to think I was just being a "wimp." We had no clue what was wrong, but we knew something sure was. Finally, we went to Dr. Blair Grubb at the Medical College of Ohio. He gave my illness a name. He said I had Orthostatic Intolerance. He spent a long time explaining it to us.

My 10th grade year I felt like an outcast. I was unable to make it to school at all. Some of my friends didn't even call me anymore. I didn't get invited to things anymore. It was as if their world continued to turn normally and mine was spinning out of control and I fell off the edge. They gossiped. If they had only called me I could have told them what it was like and maybe I could even explain why it happens. But they don't call anymore.

I want to be "NORMAL". I am tired of all the headaches, dizziness, and doctor appointments. I have missed out on too many things from sports, dances, to even just chatting at the lunch table. I can't read because of the blurred vision and my homework just keeps piling up. I feel really crummy a lot of the time and I can't keep caught up. The stress gets to me and then I feel even worse. It helps to know I have doctors who understand and care now and to talk to other kids through the Youth Network. It's not so lonely when other's care.

> ***A faithful friend is a medicine of life.***
>
> *Proverb*

Tips on Working With Your Pediatrician

Ask your doctor whom the contact person or nurse is that you should speak to when you call. Try to communicate with that individual when possible. It usually works best to communicate with a contact person who is familiar with your particular case.

Always specify if your call is urgent. Otherwise, allow sufficient time for returned calls. If you don't hear back within 24 hours call back and speak with your contact person.

Keep your phone line open for returned calls. If this is not possible, specify this with your contact person and make arrangements as to when you can be reached.

Request that your doctors office allow you to sit or even lay in a cool quiet location while you wait your turn. Most doctors who understand your condition will automatically accommodate your request on return visits.

Take snacks and water for your wait. Especially water!

Make copies of any medical material you have and leave it with your doctor to review.

Write up all your questions prior to your appointment.

Keep a brief simple journal of your symptoms. Don't be afraid to tell your doctor how you feel.

Always be truthful. Tell your doctor if you are trying alternative treatments.

Remember that a doctor given respect by his patients, has respect for patients.

Physicians who wish to receive copies of
The NDRF Youth Network Newsletter
should register with the NDRF.
Email Youthcordndrf@aol.com or write us at:
1301 Greengate Ct. Waldorf, MD 20601
Telephone: 301-707-6995
We recommend all Pediatricians register.

Wonder rather than doubt, is the root of all knowledge.

Abraham Hinkle

Good Grief Charlie Brown!

"Oh Rats!" said Charlie Brown, "Nobody understands me!" Did you ever feel like Charlie Brown? Like nobody understands what's going on with you? Well, you're not alone! There are many people that feel that no one understands them or understands what they are going through. They tend to keep this feeling to themselves - so people never know that they feel so misunderstood.

Charlie Brown knew what it meant for people not to like him, just because he was "a little different." It wasn't that he was sick or anything like that, but people are funny and if things aren't just the way they expect them - well...they just get weird!

This lack of understanding doesn't just happen to kids, it happens to everybody that's "a little different." The big question is, "What do you do about it?" Well, you can't just change people and what they think - so you have to be a little flexible and figure out what they will listen to. When kids, or adults (and there are lots of them) have a medical condition that makes them "a little different" - other people get **plain silly!** Other people think they "understand" but really they don't. Everybody has their own things to worry about - why should they worry about yours? Especially when you don't even look sick! **UGH! Aren't you just so tired of people saying you look fine when you feel so "Yuck"?** Remember, you don't have to convince everybody - just the people that make a difference in your life! Like your best friend; or one of the teachers you really like or maybe even a family member. If it is important to you - than it is important!

There are lots of people on your side; people who really do understand; people who really want to help. These people will help you say the things you want to say but just don't know how. So, the really neat thing is that this Newsletter and the people behind it really do care about you and want to help you. We want to know who you really want to tell your story to and what you want them to know. Then, we are going to help you do just that!

So starting right now you have a **secret group of experts who work just for you!** Ask them how to do and say the things you can't or won't, and **they will say it for you! In this Newsletter! Direct your questions to "Good Grief Charlie Brown...c/o YouthCordNDRF@aol.com** Complete confidentially will be maintained and your questions will be forwarded on to the **NDRF Youth Network secret Professional Charlie Brown's column**. The real **Charlie Brown** is a Professional and a Board Member of the NDRF and has the proper credentials and qualification to serve in this position. You are not alone and we at the NDRF understand - together we can help others appreciate what your going through and just maybe - that will make your life a little bit better. **All questions will remain anonymous and your name will not be attached. Good grief Charlie Brown we really do care!**

Donation Information

The NDRF is a non-profit organization dedicated to serving individuals impacted with Dysautonomia. Contributions can be made to: **NDRF Youth Network: c/o Debbie Dominelli 1301 GreengateCt., Waldorf, MD 20601 or Youth Network c/o NDRF 421 West 4th Street, Suite 9 Red Wing, MN 55066 No contribution is too small and every donation is deeply appreciated.** Research of these conditions has made tremendous advances recently and your donations will go far to help the continuation of research, education, and programs dedicated to helping those impacted with Dysautonomia. Visit the NDRF web site at www.ndrf.org for additional information.

Any schools/organizations wishing to do fund-raises in honor of a Youth Member impacted with Dysautonomia will be provided with educational information on Neuroscience and the Autonomic Nervous System.

Please accept my donation to the NDRF & NDRF Youth Network

If you wish your donation to go specifically to the Youth Network you must specify Youth Network on your check.

My donation is made in honor of / in memory of: (circle one)
Name: ____
Address:____
____

_____ Please notify the above individual of my support.

_____ I would like the NDRF to send me a tax-deductible receipt.

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Donation Method: _____ Check _____ MasterCard _____ Visa

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www.ndrf.org.
Main email address: ndrf@ndrf.org
Youth Network email address: ddominelli@ndrf.org or YouthCordNDRF@aol.com

The Greatest Sweetener of human life is friendship.
To raise this to the highest pitch of enjoyment,
is a secret which but few discover.

Contributed by:
Jordan Wilson (Age 14) & Tara Wilson (Age 10)
Kansas

Special Thanks to Dr. Julian Stewart and NDRF Board Member "Charlie Brown" for their efforts toward this newsletter!

C Cut Along Dotted Line For Book Mark by Amanda Dominelli, Age 10, Maryland

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The Young & The Dizzy

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Youth Network

The NDRF Youth Network Members are deeply appreciative of the doctors, nurses, and medical professionals who have come to their rescue. It is with sincere and heart felt thanks that we commend you for your compassion!

If I can stop one heart from breaking
I shall not live in vain;
If I can ease one life the aching,
Or cool one pain,
Or help one ***fainting robin***
Unto his nest again,
I shall not live in vain

♥

Emily Dickinson

NDRF Youth Network

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