

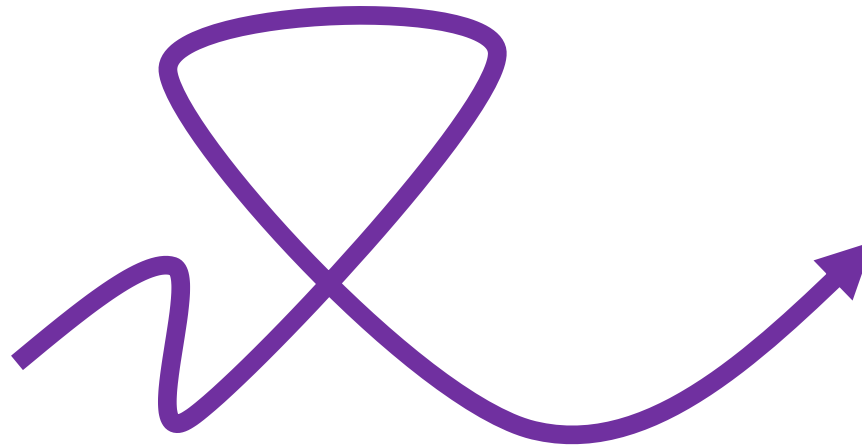
# Conquering Chiari: Diagnosis

# Path to Diagnosis

- ❖ Rapid onset of classic symptoms
- ❖ First doctor orders MRI
- ❖ Chiari is found



- ❖ Years of vague symptoms
- ❖ Many different doctors
- ❖ Misdiagnosis as “stress”
- ❖ People doubt you are sick



Chiari  
Diagnosis

*Awareness of Chiari is growing in the medical community, especially among pediatricians*

# Facts & Figures From the Chiari 1000

**45%** See 4 or more doctors before being diagnosed

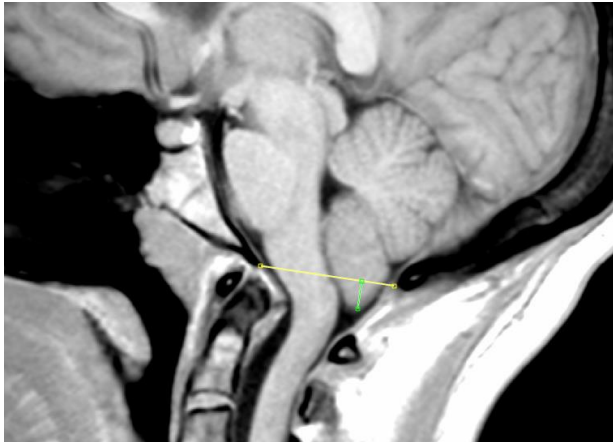
**41%** Were not actively seeking a diagnosis

**63%** Were told symptoms were in their “head”

**33** Average age of diagnosis for adult women

# Why Is Diagnosis Difficult?

Herniation does not equal symptomatic Chiari



*CHIARI*

*Most people with tonsillar herniation do not have symptomatic Chiari*

# Why Is Diagnosis Difficult?

## What symptoms are Chiari?

### Narrow Definition

Valsalva Headache

Syrinx

Muscle Atrophy or Sensory Deficits

### Broad Definition

Other types of headaches

Balance Issues

Cognitive Issues, etc.

- ❖ Many Chiari patients have other conditions, so for example whether neck pain due to cervical instability is “due” to Chiari is a matter of semantics
- ❖ Many symptoms overlap with more prevalent conditions resulting in missed and misdiagnoses

*Beyond strain headaches, the Chiari symptom picture can be confusing*

# Why Is Diagnosis Difficult?

## Doctor

Will the symptoms respond to surgery/treatment

## Patient

Looking for validation, often after being told for years there is nothing wrong with them

For the patient, although it can be difficult, it can be more useful to adopt a practical point of view....it doesn't matter if an individual symptom is "due" to Chiari or not, the question is whether surgery will improve symptoms and overall quality of life

*Doctors and patients often have different perspectives in terms of diagnosis*

# Diagnostic Process

***Because there is no single, objective test for symptomatic Chiari, the diagnostic process involves several factors that a doctor, often a neurosurgeon, will take into account in making an informed decision.***

Patient Reported Symptoms and whether they are likely caused by Chiari

Evaluation of Neurological Signs and whether they are likely caused by Chiari

MRI evidence of tonsillar herniation, compression, and spinal fluid blockage

Physician's personal experience & judgement

# Diagnostic Tests

## Most Common Tests

- ❖ **MRI** - Magnetic Resonance Imaging, creates an image of the brain and spine
- ❖ **Neurological Exam** - a way to explore what is happening to the nervous system by examining how different parts of the body respond to different forms of stimulus and functional tasks
- ❖ **Cine-MRI** - also known as phase-contrast MRI, creates an image of the flow of spinal fluid

## Other Tests

- ❖ X-Rays
- ❖ CT Scans
- ❖ Hearing & Vision
- ❖ Sleep Study
- ❖ Vestibular
- ❖ Urodynamic
- ❖ Neuropsychological

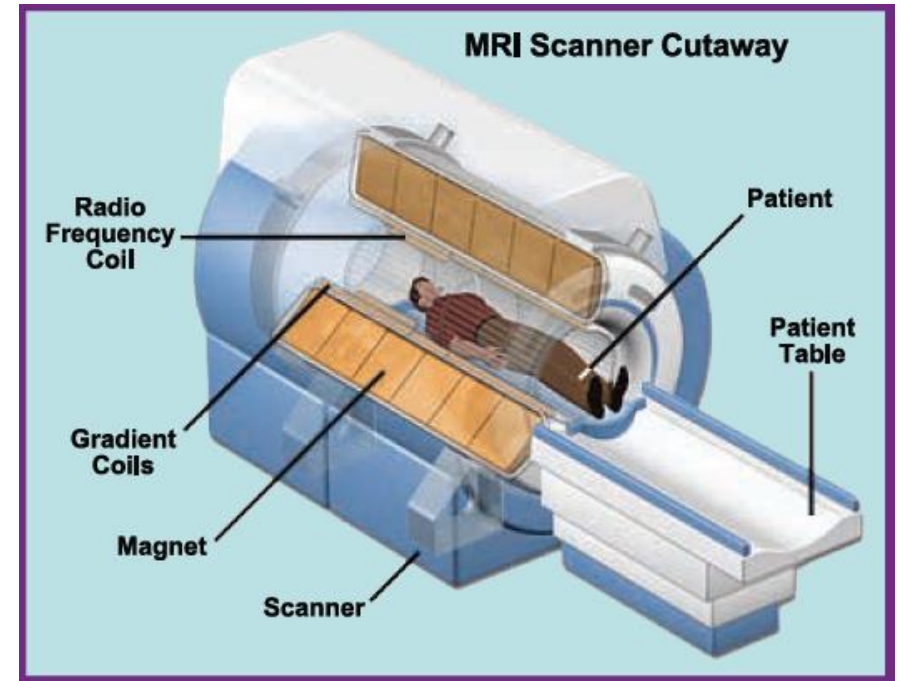
*It is recommended that Chiari patients have an MRI of their entire spine*



# Magnetic Resonance Imaging (MRI)

## The experience...

- ❖ A technician will explain the process, ask a series of questions, and lead you into the MRI room
- ❖ There you will lie down on a flat bed; it may be cold
- ❖ Because the machine is loud you will be given headphones to listen to music and so you can hear the technician
- ❖ A coil may be placed over your face like a mask; the bed will then slide into the machine
- ❖ For the next 20 minutes to 1 hour, the machine will make a series of loud noises and the bed will periodically move

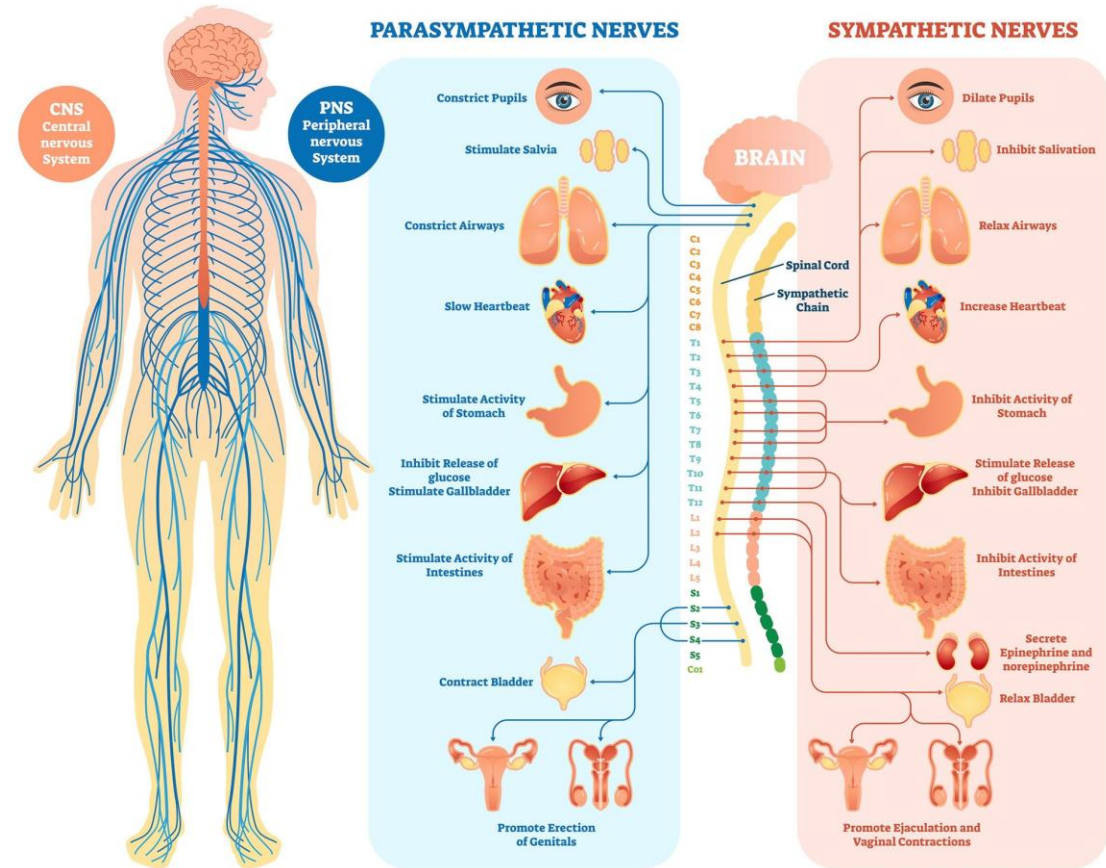


*During the first year a patient can expect to undergo several MRI scans*

# Neurological Exam

- ❖ Brainstem Function
- ❖ Cranial Nerves
- ❖ Coordination & Gait
- ❖ Motor Function
- ❖ Reflexes
- ❖ Touch & Temperature

## HUMAN NERVOUS SYSTEM



*A complete neurological exam involves many tests, however a doctor may only do enough to determine if the nervous system is compromised*

# Pediatric Diagnosis

- ❖ Children cannot always verbalize what they are feeling, sometimes the first clue is lack of proper development, either physically or cognitively
- ❖ Some children will bang their heads when they can't verbalize that their head hurts
- ❖ Symptoms may result in changes in behavior, attitude, and affect
- ❖ MRI requires the patient to remain still for an extended period of time which is not easy for a young child; young children may need to be anesthetized
- ❖ In older children, unusual presentations of scoliosis are a strong indication that an MRI should be performed



# Reacting to the Diagnosis

## Most people react one of two ways

- For patients whose symptoms came on suddenly, the diagnosis can come as quite a shock
- For patients who have struggled for years to find out what is wrong with them, a final diagnosis lends a sense of relief and vindication

## Rapid or worsening of symptoms

- Awareness of disease makes some people more in tune with what is going on in their body
- Symptoms that were in the background prior to a diagnosis are brought to the forefront

## Connecting every symptom to Chiari

- Second-order symptoms can develop, which aren't normally attributed to Chiari, but can be a result of life-style changes due to Chiari
- The broad array of symptoms that Chiari can cause makes it difficult to say whether a given symptom is "due" to Chiari

# Summary

- ❖ The lack of an objective, definitive test for symptomatic Chiari is a problem that results in some people taking years to diagnose
- ❖ Diagnosis is made through a combination of imaging, neurological exam, patient reported symptoms, and a doctor's past experience with Chiari
- ❖ Very young children may exhibit behavior changes since they can't verbalize symptoms like headaches
- ❖ A significant number of people are found to have tonsillar herniation incidentally, meaning they were not seeking a diagnosis
- ❖ People react in different ways to receiving a diagnosis; often depending on whether and how long they have been looking for one

Learn More in the [Conquer Chiari Library](#)