INTERNATIONAL FOXP1 FOUNDATION

RECOGNITION MATTERS:

Why FOXP1 Syndrome Needs Its Own ICD-10 Code

What is FOXP1 Syndrome?

FOXP1 Syndrome is a **rare genetic disorder** marked by:

- **Delayed early motor and language development**
- **Varying intellectual disabilities**
- **Behavioral challenges**
- **Difficulties with speech and language**

WHAT DOES "ICD" STAND FOR?
International Classification of Diseases
There are both **ICD-10** and **ICD-11** systems, currently.

WHAT IS IT?
A standardized system, maintained by the World Health Organization, used to code diseases and medical conditions.

WHY DOES IT MATTER?
This system establishes medical necessity and is required for all HIPAA-covered claims

The Problem:

FOXP1 Syndrome *does not* have a dedicated ICD-10 code

Current representation:

Current FOXP1 Syndrome representation in ICD-10 code falls within a general description of *similar conditions* and *symptoms*.

Chapter 06 of ICD-10 code:
General information about mental, behavioral, and neurodevelopmental disorders.

Why is this a problem?

Providers reference *different* categories within Chapter 06

Variability in details and diagnoses of FOXP1 Syndrome

Specific code allows for more *accurate* and *consistent* diagnoses

Why does this matter to families?

A SPECIFIC ICD-10 CODE HELPS ENSURE CHILDREN WITH FOXP1 SYNDROME ARE SEEN, UNDERSTOOD, AND SUPPORTED.

It is difficult to navigate a medical system that does not clearly understand the condition,
without a proper ICD-10 Code:

- **Inconsistent insurance coverage**
- **Providers may lack clarity about FOXP1 Syndrome... medical records may not fully reflect a proper diagnosis**
- **Decreased access to therapies and treatments**

Advancing Research + Empowering Families

Why advocate for this?

Your child's diagnosis is clearly recognized

Care teams can communicate easily

Easier access to insurance & services

FOXP1 is visible in healthcare systems

How does this help your child?

A dedicated code leads to:

- **Clear, consistent medical records**
- **Better coordinated care**
- **More reliable insurance coverage**
- **More research and awareness**

What makes an ICD-10 code **proposal** successful?

High Detail Level
Complete explaination of code proposal and disease

Support from Documentation
Signs, symptoms, diagnosis, treatment

Financial Accuracy
Knowing the true cost of care and treatments

Clinical Relevance
Aligns with physicians' treatment plans, current research, and public health

What about an **ICD-11** code?

ICD-11 is the newest classification system for coding diseases which has been implemented in some countries *outside the U.S.*

The U.S. has not yet transitioned to the ICD-11 due to:

- **High transition costs**
- **Need for a U.S. specific version of ICD-11**
- **Lack of an implementation timeline**

When the U.S. ultimately adopts the ICD-11 system in the future, medical conditions need to be re-evaluated and reorganized.

This allows for **greater specificity** and **future additions**.

> INTERNATIONALLY, FOXP1 PATIENTS **FACE THE SAME ISSUES** AS THOSE IN THE U.S. WITHOUT AN ICD-11 CODE.

What can families do?

Ask questions
Ask your provider: "*What ICD-10 code is being used for my child?*"

Share your story
Personal experiences drive awareness and change

Review medical records
Make sure your child's diagnosis is clearly documented.

Get genetic testing!
If your child has an unexplained intellectual disability

Stay connected
Engage with the International FOXP1 Foundation

HOW TO APPLY FOR AN *ICD-10 Code*

INTERNATIONAL FOXP1 FOUNDATION

1 SUBMIT A PROPOSAL

Stakeholders such as doctors, hospitals, patient advocacy organizations, professional societies, and researchers can submit a proposal.

2 PUBLIC PRESENTATION

Together with the **ICD-10-CM Coordination & Maintenance Committee**, the CMS, CDC, and the public can ask questions at the public presentation.

CMS CENTERS FOR MEDICARE & MEDICAID SERVICES

Centers for Disease Control and Prevention
National Center for Health Statistics

3 PROPOSAL RECOMMENDATIONS

After the public meeting presentation, stakeholders may:

Submit written comments | *Suggest modifications* | *Support or oppose the proposal*

4 DECISION OUTCOME

Proposals can be deferred for additional data, modified before approval, or rejected if there is insufficient justification. New codes are implemented on **October 1st** of the following fiscal year.

The medical coding landscape is *constantly evolving*...

the International FOXP1 Foundation strives to ensure *accurate representation* of FOXP1 Syndrome within it.

INTERNATIONAL FOXP1 FOUNDATION

EVERYLIFE FOUNDATION FOR RARE DISEASES

Rare Giving LIFTING EVERY VOICE

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The International FOXP1 Foundation is a 501(c)3 dedicated to supporting those impacted by FOXP1 Syndrome

The International FOXP1 Foundation received a Rare Giving Grant from the EveryLife Foundation for Rare Diseases to help pursue an ICD-10 code.