

Pause for The GFPD Op-Ed 2024 Templates

Instructions:

- 1. Locate an Op-Ed template from the choices below that best matches your family (bereaved parent or not, adult patient, type of peroxisomal disorder, etc.)
- 2. Copy and paste the template to your own document.
- 3. Customize the template to fit you and your family.
- 4. Submit to your local newspaper. This is usually through an online form on their website.
- 5. Let the GFPD know when your Op-Ed runs in the newspaper by contacting Katie at katie@thegfpd.org

Glossary of Terms:

PBD-ZSD = Peroxisomal Biogenesis Disorder – Zellweger Syndrome Disorder
DBPD = D-Bifunctional Protein Deficiency
ACOX = Acyl-CoA Oxidase Deficiency
AMACRD = 2-Methylacyl-CoA racemase Deficiency

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<u>Template for Parent(s) of Child(ren) Who Died from a</u> <u>Peroxisomal Biogenesis Disorder in the Zellweger Spectrum (PBD-ZSD)</u>

To the Editor:

October 5th is a special day for our family as we celebrate *Pause for The GFPD*, the annual awareness day of The Global Foundation for Peroxisomal Disorders (GFPD). I invite the NEWSPAPER NAME readership to join our family and PAUSE for families impacted by peroxisomal disorders in more than 40 countries around the world.

OUR/MY DAUGHTER/SON, NAME, lived for _____ months/years with a peroxisomal biogenesis disorder in the Zellweger spectrum (PBD-ZSD). CHILDS NAME is one of fewer than 1,000 children worldwide affected with PBD-ZSD. TELL 1-3 SENTENCES ABOUT YOUR CHILD.

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On October 5th, we are celebrating all that the GFPD has accomplished in the last 14 years in moving towards a cure for peroxisomal disorders. Most importantly, *Pause for The GFPD* celebrates the beautiful children affected by this rare, terminal condition. We invite you to help the GFPD – and our global community of patients, families, caregivers, scientists, and medical professionals – raise awareness about the need for treatments and cures for this rare, genetic, and terminal disease.

Raising public awareness makes a difference. It gives families hope and can lead to new, lifesaving treatments. Taking the time to participate in *Pause for The GFPD* also helps those of us who have lost a child to know our child is still loved and remembered. I encourage everyone reading this to get involved by visiting the GFPD website: <u>http://www.thegfpd.org</u>, or find us on Facebook, Instagram, or Twitter @thegfpd to learn about *Pause for The GFPD* celebrations in your area, ways you can help make a difference, and to learn more about the groundbreaking work the GFPD is doing around the world.



<u>Template for Parent(s) of Child(ren) Living with a</u> <u>Peroxisomal Biogenesis Disorder in the Zellweger Spectrum (PBD-ZSD)</u>

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OUR/MY DAUGHTER/SON, NAME, is HOW MANY years old and is one of fewer than 1,000 children living worldwide with a peroxisomal biogenesis disorder in the Zellweger spectrum (PBD-ZSD). TELL 1-3 SENTENCES ABOUT YOUR CHILD. PBD-ZSD is a rare, genetic, condition affecting multiple organ systems in the body, and is generally fatal in childhood.

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<u>Template for Adult Living with a</u> Peroxisomal Biogenesis Disorder in the Zellweger Spectrum (PBD-ZSD)

To the Editor:

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I am one of fewer than 1,000 individuals living worldwide with a peroxisomal biogenesis disorder in the Zellweger spectrum (PBD-ZSD). TELL 1-3 SENTENCES ABOUT YOURSELF AND HOW PBD IMPACTS YOUR LIFE. PBD-ZSD is a rare, genetic, condition affecting multiple organ systems in the body, and is generally fatal in childhood.

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<u>Template for Parent(s) of a Child(ren) Who Died From</u> <u>D-Bifunctional Protein Deficiency (DBPD)</u>

To the Editor:

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OUR/MY DAUGHTER/SON, NAME, lived for _____ months/years with a peroxisomal disorder called, d-bifunctional protein deficiency (DBPD). TELL 1-3 SENTENCES ABOUT YOUR CHILD.

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Template for Parent(s) of Child(ren) Living with D-Bifunctional Protein Deficiency (DBPD)

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OUR/MY DAUGHTER/SON, NAME, is HOW MANY years old and is one of only a few children living worldwide with a peroxisomal disorder called, d-bifunctional protein deficiency (DBPD). TELL 1 - 3 SENTENCES ABOUT YOUR CHILD. DBPD is a rare, genetic, condition affecting multiple organ systems in the body, and is generally fatal in childhood.

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<u>Template for Adult(s) Living with</u> <u>D-Bifunctional Protein Deficiency (DBPD)</u>

To the Editor:

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I am one of only a few in the world who are living with a peroxisomal disorder called dbifunctional protein deficiency (DBPD). TELL 1-3 SENTENCES ABOUT YOURSELF AND HOW DBPD IMPACTS YOUR LIFE. DBPD is a rare, genetic, condition affecting multiple organ systems in the body, and is generally fatal in childhood.

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Template for Parent(s) of a Child(ren) Who Died From Acyl-CoA Oxidase Deficiency (ACOX)

To the Editor:

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OUR/MY DAUGHTER/SON, NAME, lived for _____ months/years with a peroxisomal disorder called, Acyl-CoA Oxidase Deficiency (ACOX). TELL 1-3 SENTENCES ABOUT YOUR CHILD.

Pause for The GFPD is a day that brings our family hope for the future. The GFPD is a 501(c)(3) nonprofit public charity founded in Tulsa, Oklahoma in 2010 to support families affected by peroxisomal disorders and to directly fund medical research.

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Template for Parent(s) of Child(ren) Living with Acyl-CoA Oxidase Deficiency (ACOX)

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OUR/MY DAUGHTER/SON, NAME, is HOW MANY years old and is one of only a few children living worldwide with a peroxisomal disorder called, Acyl-CoA Oxidase Deficiency (ACOX). TELL 1 -3 SENTENCES ABOUT YOUR CHILD. ACOX is a rare, genetic, condition affecting multiple organ systems in the body, and is generally fatal in childhood.

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<u>Template for Adult Living with</u> <u>Acyl-CoA Oxidase Deficiency (ACOX)</u>

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I am one of only a few in the world who are living with a peroxisomal disorder called Acyl-CoA Oxidase Deficiency (ACOX). TELL 1-3 SENTENCES ABOUT YOURSELF AND HOW ACOX IMPACTS YOUR LIFE. ACOX is a rare, genetic, condition affecting multiple organ systems in the body, and is generally fatal in childhood.

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Template for Parent(s) of Child(ren) Who Died From 2-Methylacyl-CoA racemase Deficiency (AMACRD)

To the Editor:

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Template for Parent(s) of Child(ren) Living with 2-Methylacyl-CoA racemase Deficiency (AMACRD)

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I am one of only a few in the world who are living with a peroxisomal disorder called 2-Methylacyl-CoA racemase Deficiency (AMACRD). TELL 1-3 SENTENCES ABOUT YOURSELF AND HOW AMACRD IMPACTS YOUR LIFE. AMACR Deficiency is a rare, genetic, condition.

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