

Pause for The GFPD Op-Ed 2022 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

Templates Available:

| | |
|----------------------------------|----|
| PBD-ZSD Bereaved Parent..... | 2 |
| PBD-ZSD Non-Bereaved Parent..... | 3 |
| PBD-ZSD Adult Patient | 4 |
| DBPD Bereaved Parent | 5 |
| DBPD Non-Bereaved Parent..... | 6 |
| DBPD Adult Patient | 7 |
| ACOX Bereaved Parent | 8 |
| ACOX Non-Bereaved Parent..... | 9 |
| ACOX Adult Patient | 10 |
| AMACRD Bereaved Parent..... | 11 |
| AMACRD Non-Bereaved Parent | 12 |
| AMACRD Adult Patient | 13 |

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

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.

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.

On October 5th, we are celebrating all that the GFPD has accomplished in the last 12 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, life-saving 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: <http://www.thegfpd.org>, 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.

Sincerely,
YOUR NAME
YOUR CITY, YOUR STATE

**Template for Parent(s) of Child(ren) Living with a
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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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**Template for Adult Living with a
Peroxisomal Biogenesis Disorder in the Zellweger Spectrum (PBD-ZSD)**

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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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**Template for Parent(s) of a Child(ren) Who Died From
D-Bifunctional Protein Deficiency (DBPD)**

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)**

To the Editor:

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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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**Template for Adult(s) Living with
D-Bifunctional Protein Deficiency (DBPD)**

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I am one of only a few in the world who are living with a peroxisomal disorder called d-bifunctional 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.

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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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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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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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