

## **Parent Op-Ed Templates for Pause with the GFPD 2025**

### **Instructions:**

1. Choose an Op-Ed template that fits your family.
2. Copy it into your own document and customize it.
3. Submit it to your local newspaper (usually via their website).
4. Notify GFPD when it runs by emailing Katie at [katie@thegfpd.org](mailto:katie@thegfpd.org) and/or Margaret at [margaret@mcrbranding.com](mailto:margaret@mcrbranding.com).

### **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

### **Parent Templates Available:**

Non-Bereaved Parent (PBD-ZSD).....	2
Non-Bereaved Parent (DBPD).....	3
Non-Bereaved Parent (ACOX).....	4
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Both Bereaved and Non-Bereaved Parent .....	10

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

To the Editor:

October 5<sup>th</sup> is a special day for our family as we celebrate *Pause with 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, 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.

*Pause with the GFPD* is a day that brings our family hope. 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 5<sup>th</sup>, we are celebrating all that the GFPD has accomplished in the last 15 years in moving towards a cure for peroxisomal disorders. Most importantly, *Pause with 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. I encourage everyone reading this to get involved by visiting the GFPD website: <http://www.thegfpd.org>, or find us on Facebook, Instagram, or X @thegfpd to learn about *Pause with 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  
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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**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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**Template for Parent(s) of Child(ren) Living with  
2-Methylacyl-CoA racemase Deficiency (AMACRD)**

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, 2-Methylacyl-CoA racemase Deficiency (AMACRD). TELL 1 -3 SENTENCES ABOUT YOUR CHILD. AMACR Deficiency is a rare, genetic, condition.

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

To the Editor:

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

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

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OUR/MY DAUGHTER/SON, NAME, lived for \_\_\_\_\_ months/years with a peroxisomal disorder called, 2-Methylacyl-CoA racemase Deficiency (AMACRD). TELL 1-3 SENTENCES ABOUT YOUR CHILD.

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**Template for Parent(s) Who are Both Bereaved  
and Caring for Children Living with a Peroxisomal Disorder**

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OUR/MY DAUGHTER/SON, NAME, died at age \_\_\_\_ months/years from a peroxisomal disorder, and OUR/MY DAUGHTER/SON, NAME is living with a peroxisomal disorder. TELL 1-3 SENTENCES ABOUT YOUR CHILDREN.

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## **Grandparent Op-Ed Templates for Pause with the GFPD 2025**

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2. Copy it into your own document and customize it.
3. Submit it to your local newspaper (usually via their website).
4. Notify GFPD when it runs by emailing Katie at [katie@thegfpd.org](mailto:katie@thegfpd.org) and/or Margaret at [margaret@mcrbranding.com](mailto:margaret@mcrbranding.com).

### **Glossary of Terms:**

- PBD-ZSD = Peroxisomal Biogenesis Disorder – Zellweger Syndrome Disorder (this includes the historically described Zellweger's, NALD, IRD, and Heimler)
- DBPD = D-Bifunctional Protein Deficiency
- ACOX = Acyl-CoA Oxidase Deficiency
- AMACRD = 2-Methylacyl-CoA racemase Deficiency

### **Parent Templates Available:**

Non-Bereaved Grandparent (PBD-ZSD) .....	2
Non-Bereaved Grandparent (DBPD) .....	3
Non-Bereaved Grandparent (ACOX) .....	4
Non-Bereaved Grandparent (AMARCD) .....	5
Bereaved Grandparent (PBD-ZSD) .....	6
Bereaved Grandparent (DBPD) .....	7
Bereaved Grandparent (ACOX) .....	8
Bereaved Grandparent (AMACRD) .....	9
Both Bereaved and Non-Bereaved Grandparent .....	10

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

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OUR/MY GRANDDAUGHTER/SON is HOW MANY MONTHS/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 GRANDCHILD. PBD-ZSD is a rare, genetic, condition affecting multiple organ systems in the body, and is generally fatal in childhood.

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D-Bifunctional Protein Deficiency (DBPD)**

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

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OUR/MY GRANDDAUGHTER/SON lived for \_\_\_\_ MONTHS/YEARS with a peroxisomal biogenesis disorder in the Zellweger spectrum (PBD-ZSD). OUR/MY GRANDDAUGHTER/SON is one of fewer than 1,000 children worldwide affected with PBD-ZSD. TELL 1-3 SENTENCES ABOUT YOUR GRANDCHILD.

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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 with the GFPD* also helps those of us who have lost a grandchild to know they are 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 X @thegfpd to learn about *Pause with 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 Grandparent(s) of a Child(ren) Who Died From  
Acyl-CoA Oxidase Deficiency (ACOX)**

To the Editor:

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Sincerely,  
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YOUR CITY, YOUR STATE

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

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OUR/MY GRANDDAUGHTER/SON lived for \_\_\_\_\_ MONTHS/YEARS with a peroxisomal disorder called, 2-Methylacyl-CoA racemase Deficiency (AMACRD). TELL 1-3 SENTENCES ABOUT YOUR GRANDCHILD.

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Sincerely,  
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YOUR CITY, YOUR STATE

**Template for Grandparent(s) Who are Both Bereaved  
and Have a Grandchild(ren) Living with a Peroxisomal Disorder**

To the Editor:

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OUR/MY GRANDDAUGHTER/SON died at age \_\_\_\_ MONTHS/YEARS from a peroxisomal disorder, and OUR/MY GRANDDAUGHTER/SON is also living at age \_\_\_\_ MONTHS/YEARS with a peroxisomal disorder. TELL 1-3 SENTENCES ABOUT YOUR GRANDCHILDREN WHO HAD & HAVE THIS DISEASE.

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## **Adult Warrior Op-Ed Templates for Pause with the GFPD 2025**

### **Instructions:**

- Choose an Op-Ed template that matches the type of peroxisomal disorder you have
- Copy it into your own document and customize it.
- Submit it to your local newspaper (usually via their website).
- Notify GFPD when it runs by emailing Katie at [katie@thegfpd.org](mailto:katie@thegfpd.org) and/or Margaret at [margaret@mcrbranding.com](mailto:margaret@mcrbranding.com).

### **Glossary of Terms:**

- **PBD-ZSD** = Peroxisomal Biogenesis Disorder – Zellweger Syndrome Disorder (this includes the historically described Zellweger’s, NALD, IRD, and Heimler)
- **DBPD** = D-Bifunctional Protein Deficiency
- **ACOX** = Acyl-CoA Oxidase Deficiency
- **AMACRD** = 2-Methylacyl-CoA racemase Deficiency

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Adult with DBPD .....	3
Adult with ACOX .....	4
Adult with AMACRD .....	5

**Template for an Adult Living with a  
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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**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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Acyl-CoA Oxidase Deficiency (ACOX)**

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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

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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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