

### **Grandparent 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 <a href="mailto:katie@thegfpd.org">katie@thegfpd.org</a> and/or Margaret at <a href="mailto:margaret@mcrbranding.com">margaret@mcrbranding.com</a>.

### **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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### Template for Grandparent(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 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.

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: <a href="http://www.thegfpd.org">http://www.thegfpd.org</a>, 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.



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

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OUR/MY GRANDDAUGHTER/SON is HOW MANY MONTHS/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 Grandparent(s) of Child(ren) Living with Acyl-CoA Oxidase Deficiency (ACOX)

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

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OUR/MY GRANDDAUGHTER/SON is HOW MANY MONTHS/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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## 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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## Template for Grandparent(s) of a Child(ren) Who Died From D-Bifunctional Protein Deficiency (DBPD)

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

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

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

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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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