

Xeroderma Pigmentosum Family Support

Executive Director / CEO

June 9, 2026

This analysis benchmarks the total compensation of **Michele Milota, Executive Director / CEO** (\$25,000) against **every comparable organization** that fit the selection criteria — **27** in total — drawn systematically from IRS Form 990 filings, not a hand-picked subset.

Compensation sits at approximately the **48th** percentile of comparable organizations within the typical range

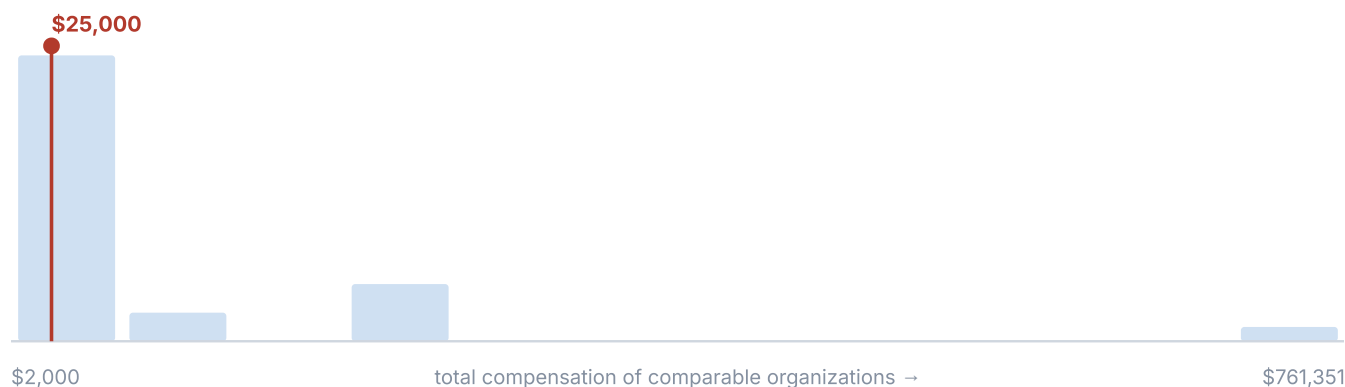
Benchmarked executive: Michele Milota — reported title “CO-EXECUTIVE DIRECTOR”, a **direct title match** to the Executive Director / CEO role.

How comparable organizations were selected

SECTOR	Organizations sharing the subject's NTEE classification (H80).
BUDGET	Total revenue between \$57,189 and \$128,037 — 0.67x to 1.50x the subject's \$85,358 (the band tightens as size grows).
GEOGRAPHY	Same NTEE major group (H), nationwide + budget 0.67–1.5x revenue.

27 organizations qualified on sector, size, and geography → **27** within the band form the benchmarked peer set.

Distribution of comparable compensation



\$5,368	\$10,007	\$26,573	\$69,412	\$222,343	\$25,000
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■ Comparable organizations

Each figure is Form 990 Part VII columns D + F (reportable pay plus other compensation and benefits; column F may include amounts from related organizations), normalized to CA cost of living (BEA RPP, 2023) and to its filing year (CPI-U); the reported amount is on each linked 990.

ORGANIZATION	STATE	REVENUE	MATCHED TITLE	COMP (REPORTED)	COMP (ADJUSTED)	FY
The Parkinson Alliance Inc	NJ	\$85,580	President & Ceo	\$57,692	\$59,652	2024
Arizona Infectious Disease Society Inc	AZ	\$84,010	President	\$6,900	\$7,685	2024
The International Genomics Consortium	AZ	\$83,902	Ceo	\$663,981	\$761,351	2023
Rpa Research & Education Foundation	MD	\$87,336	Executive Director	\$17,583	\$19,037	2024
Beth Israel Deaconess Department Of	MA	\$89,438	Director (Ex-officio) (Hmfp Ceo)	\$109,829	\$114,295	2024
Northeast Osteopathic Medical	ME	\$90,000	Executive Di	\$180,075	\$214,988	2023
Cardiovascular & Imaging Research Foundation Of Ny	NY	\$90,731	Principal Investigator	\$200,000	\$215,475	2023
Post-finasteride Syndrome Foundation	NJ	\$91,449	President	\$24,000	\$24,815	2024
The Tiller Foundation	AZ	\$93,604	President & Director	\$24,000	\$27,520	2023
Val Skinner Foundation Inc	NJ	\$96,009	Chairperson	\$7,500	\$7,755	2024
Children's Cancer Aid And Research Institute	AZ	\$98,592	President	\$29,575	\$32,939	2024
Northwell Health Medical Pa Pc	NY	\$71,513	Ceo	\$75,656	\$79,172	2024
Anchorage York Rite Foundation Inc	AK	\$102,219	Secretarytreasurer	\$5,680	\$6,289	2024
Tri County Development Corp	TN	\$102,667	President/ceo	\$8,413	\$10,241	2024

ORGANIZATION	STATE	REVENUE	MATCHED TITLE	COMP (REPORTED)	COMP (ADJUSTED)	FY
The Healthy Birth And Infant Brains	WY	\$67,642	Executive Director	\$20,000	\$24,802	2024
Allergists For Israel	OH	\$106,610	Administrator	\$3,250	\$3,986	2024
The Alliance For Benzodiazepine Best Practices	OR	\$109,326	Medical Director	\$24,000	\$26,573	2023
The Foundation For Embryonic Competence	NJ	\$60,778	Scientific Director	\$225,000	\$232,645	2024
The Salgi Esophageal Cancer Research Foundation	RI	\$110,298	Vice President	\$8,800	\$9,772	2024
University Kidney Research Organization	CA	\$110,733	President	\$2,000	\$2,000	2024
Heart And Stroke Research Fund	AZ	\$112,297	President	\$2,000	\$2,170	2025
Ghost Tree Invitational Ltd	OR	\$112,403	Vice Preside	\$12,000	\$12,905	2024
Mind First Foundation	MA	\$58,286	President	\$232,667	\$242,129	2024
Detroit International Research And	MI	\$116,460	Executive Di	\$25,992	\$31,069	2024
Vincera Foundation	PA	\$116,830	Executive Dir.	\$30,000	\$34,646	2024

Comp (reported) is the figure on each organization's Form 990 (columns D + F); **Comp (adjusted)** normalizes it to CA cost of living and 2024 dollars. Click any organization to verify the figure on ProPublica.

● Methodology

Comparable organizations were drawn from electronically filed IRS Form 990 returns and matched on sector (NTEE code), budget (a size-adaptive revenue band that tightens as the organization grows), and geography (same-state first, broadening only when too few peers qualify); every organization within the band forms the peer set. To compare fairly across regions and years, peer compensation is normalized to CA cost of living (BEA Regional Price Parities, 2023) and to the subject's filing year (CPI-U). The figure benchmarked is Form 990 Part VII, Section A, columns D + F — reportable pay plus other compensation, benefits, and deferred amounts (column F may include amounts from related organizations) — with the chief executive matched by role. Related-organization amounts (column E) and institutional trustees are excluded. Full methodology: peerbasis.org/methodology.

● Sample, role match & sensitivity

PEER COUNT	27 organizations. Compensation range \$2,000–\$761,351; filing years 2023–2025.
SIZE BASIS	Matched on total revenue (\$85,358); for reference, expenses \$146,798 and assets \$125,571. Revenue and expenses diverge this year — revenue may misrepresent operating size; weigh the expense-based view.
ROLE MATCH	Michele Milota, reported title " <i>CO-EXECUTIVE DIRECTOR</i> ", benchmarked as Executive Director / CEO. The title maps directly to this role.
RELATED-ORG PAY	5 peers report related-organization compensation (column E), which the D + F benchmark does not fully capture; review where material.
OUTLIERS	5 peers fall outside 1.5× the interquartile range — consider whether any reflect one-time payments (severance, deferred-comp payouts).

Sensitivity — the subject's percentile under alternative compensation definitions:

BASIS	SUBJECT PERCENTILE
Total compensation (D + F), cost-of-living + inflation adjusted — the PeerBasis default	48 th
Total compensation (D + F), as reported (no adjustments)	59 th
Reportable pay only (column D), adjusted	59 th
All sources (D + E + F), adjusted	41 st

If the percentile moves materially across these definitions, the result is sensitive to methodology choices, and the board should weigh which basis best fits its facts.

● Rebuttable presumption of reasonableness · 26 CFR 53.4958-6

Compensation paid by a tax-exempt organization is presumed reasonable — shifting the burden to the IRS — when three requirements are met. This report supplies the comparability data for the second. The board should record the following in its minutes *concurrently* with its decision:

Draft board minutes – executive compensation

1. The compensation of the Executive Director / CEO (Michele Milota) was approved in advance by [the Board / Compensation Committee], composed of members with no conflict of interest with respect to the arrangement.
2. Prior to its determination, the authorized body obtained and relied upon appropriate comparability data, namely the PeerBasis Compensation Comparability Determination dated June 9, 2026, comparing compensation against 27 similarly situated organizations (Same NTEE major group (H), nationwide + budget 0.67–1.5× revenue).

3. The authorized body determined that total compensation of \$25,000 is reasonable (approximately the 48th percentile of comparable organizations) and documented the basis for this determination concurrently, on [date], by a vote of [__ for / __ against].

Sources: IRS Form 990 e-file data (apps.irs.gov); IRS Business Master File (NTEE classification). Every figure traces to an original public filing — click any organization above to verify it on ProPublica. PeerBasis is a service of Prismind Analytics; its [methodology is published](#), was commissioned for independent adversarial review, and discloses its own limitations. This report is comparability data to support a board's good-faith determination under IRC 4958; it is not legal or tax advice. Generated by PeerBasis on June 9, 2026.