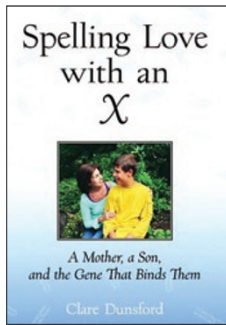


Blood-strong love



Spelling Love with an X: A Mother, a Son, and the Gene that Binds Them

By Clare Dunsford

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Reviewed by Sharon F Terry

Science, when it intersects with emotion, can be obscured; and the experience of living with disease, when described by a parent, is often moving but not necessarily substantive. Clare Dunsford, whose son J.P. was born with fragile X syndrome (FXS), deftly gives space to all dimensions of her son's diagnosis. She plunges the reader into a phenomenal mélange of genetics, relationships, poetry, faith and humor in *Spelling Love with an X*.

Striving to decode her son's often scrambled thought and speech, she paints this image: "...I have to catch meaning on the fly, feint and dodge to feel it hit, but when it does... it hits home." Readers of this remarkable book do not have to "catch meaning on the fly." Dunsford eloquently and directly shares her growing understanding of J.P.'s mutation responsible for FXS, in poetry and prose, in scientific terms and in plain speak.

Concurrent with her awareness of her son's need to shield "himself from an unbearable intimacy," Dunsford calls us to that intimacy, and at times it does feel almost unbearable. Not for the guilty, pull-at-your-heartstrings sentiment that a special-needs child often evokes, but for the startling truth and authenticity with which she invites us into their lives. This liberates the reader to dive deeply into the meaning of a life that falls short of the Platonic ideal, and indeed, it unleashes the abundant richness of this life.

Dunsford teaches us to read the misspelled genome with new eyes, appreciating her declaration that "My love for poetry, its melting obscurity, is met by the poetry of J.P.'s speech, our symbiosis as inevitable and paradoxical as the Word and Flesh—the delicately mutating X in me coming to flower in the full extravagance of my son's mutant X. He is the poet I'd like to be, and I am his reader." This is the other side, and necessary counterpart, of instruments that read the sequence of the human genome. Here, we need not struggle to design algorithms that interpret accurately. Dunsford shows us that the human heart comes prepared to resonate with these primal truths.

With great scientific dexterity, she integrates the genetic dimension—the coming to terms with the meaning of misspellings in one's genome

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and with the imperfections that nature and nurture impart. As society struggles to become more literate about scientific concepts, this book offers nonscientists a meaningful way to grasp genetic concepts such as genes, proteins and inheritance. Scientists are offered the gift of seeing the demonstrated relevance of their work.

Dunsford draws the reader through her own limitations, revealing her unfolding realization of the beauty of the imperfect, yet managing not to diminish the effects of such imperfection. She writes: "In writing this book, I break that silence." Although Dunsford is referring to the silence of her family in directly addressing FXS, she also breaks the silence within many other systems: faith and suffering, profound fears of the 'abnormal', discord in research paradigms, the beauty of the genome as manifest in a human being, and the 'ideal' in culture and science.

Even as carriers of FXS seek to understand if they are in some way 'affected', she realizes that these carriers of recessive diseases "will be increasingly forced to ask whether a diagnosis applies to us as well as our children" in a genomic age. She pairs this nascent concept in genetics with the words of nineteenth-century poet Gerard Manley Hopkins, about whom she wrote her dissertation: "I taste self at but one tankard, that of my own being." Poets, it seems, understood the complexities of genetics well before the genomic age!

In this age, the sequence of the human genome has been likened by presidents (Bill Clinton) and great scientists (Francis Collins) to the 'Book of Life'. Although this may be a profound and beautiful metaphor, it is not easy to integrate science into our conception of ancestral descent, particularly if we pass on misspellings in our DNA. All of us carry mutations that could potentially cause disease, but only some of us know the burden of transferring those mutations to our children. Rather than run from these bonds, Dunsford proclaims her "...sense of connection to all ancestors because of 'wayward nucleotides that danced in my family's blood.'"

Whether one studies *Drosophila*, develops therapies for common conditions, or lives with someone affected by a genetic condition, this book makes essential connections. Science and poetry, shame and pride, and sense and prattle are all coaxed into relationship, allowing readers from any vantage point to grasp the whole. Speaking for research subjects, be they amoebas or humans, Dunsford asks that her story, in humor and pain, be called "an unexpected blurt of sentience from the presumably inert." Scientists are called in this book to see the human face of their work, and those who live with disease are called to "inflect the drumbeat of DNA that courses through us so that it yields a rhythm we can dance to." I believe Clare Dunsford when she says "And dance we will."

Far from being the depressive tome that so many stories of living with a disease are, this book leaves us with this: "I still had these: an unquenchable belief that in and under life lay poetry; a constitutional hunger for order over chaos; a mother's blood-strong love for her child. X does not always herald the end of the alphabet. In the scrambled syntax of our new life, it is in some ways just the beginning." More than anything, Dunsford shows us that we can navigate life's crossings with grace.